



**Integrating patients' experiences, understandings and
enactments of infection prevention and control into
clinicians' everyday care: A video-reflexive-ethnographic
exploratory intervention**

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Submitted in fulfilment of the requirements for the Degree of Doctor of Philosophy

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Dedication

I dedicate this thesis to all of the patients who shared their experiences and understandings of healthcare-associated infection and infection prevention and control. In particular I would like to thank those who have shared this entire PhD journey with me. James, Destiny, Gary, Rob and June; you are my co-researchers and friends and I cannot thank you enough.

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Finally, my deepest thanks to the truly incredible patients and nurses and other staff who volunteered their time and expertise to undertake this research with me so that together we could all make a difference.

Statement of Original Authorship

This thesis contains no material which has been accepted for a degree or diploma by the University of Tasmania or any other institution, except by way of background information and duly acknowledged in the thesis, and to the best of my knowledge and belief no material previously published or written by another person except where due acknowledgement is made in the text of the thesis, nor does the thesis contain any material that infringes copyright.

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Statement of Ethical Conduct

The research associated with this thesis abides by the international and Australian codes on human and animal experimentation, as approved by the Western Sydney Local Health District Human Research Ethics Committee (HREC/2012/3/4.9 (3278) AU RED HREC/11/WMEAD/34), the University of Technology Human Research Ethics Committee (UTS HREC 201-265) and the Human Research Ethics Committee (Tasmania) Network – Health and Medical (H0014583).

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Outcomes of this thesis

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Chapter 6

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Contribution to health education

Video footage that I created with patient co-researcher, Gary Armstrong, is currently being used in an infection control module produced by The Health Education and Training Institute (HETI). The module is one of the core online mandatory training packages that must be undertaken by all by NSW Health staff (<http://www.heti.nsw.gov.au/Programs/Mandatory-Training/>).

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Glossary of abbreviations

ABHR	Alcohol based hand rub
CDC	Centers for Disease Control and Prevention
CHC	Centre for Health Communication
CNC	Clinical nurse consultant
CNE	Clinical nurse educator
EBCD	Experience-based co-design
HAI	Healthcare associated infection
ICP	Infection control practitioner
IPC	Infection prevention and control
MRO	Multi-drug resistant organism
MRSA	Methicillin resistant <i>Staphylococcus aureus</i>
NHMRC	National Health and Medical Research Council
NUM	Nurse unit manager
PMOS	Patient measurement of safety
RN	Registered nurse
VRE	Video-reflexive ethnography
WHO	World Health Organization

Glossary of key terms

Affect	To influence or make a difference to. In this thesis, affect refers to the notion of our ability to be receptive to what goes on around us such that we are affected and in turn affect others.
Antimicrobial resistance	Resistance of a microorganism to an antimicrobial medicine to which it was previously sensitive.
Becoming	The dynamic unfolding of ‘being’ that is always immanent and moved or activated in relation to the collective body.
Clinician	Any professional undertaking clinical tasks: e.g. nurses, doctors, allied health professionals.
Cohorting	Placing together in the same room patients who are infected with the same pathogen.
Colonisation	The sustained presence of replicating infectious agents on or in the body without the production of an immune response or disease.
Contact precautions	A set of practices used to prevent transmission of infectious agents that are spread by direct or indirect contact with the patient or the patient’s environment.
Distributed intelligence	Refers to actors reflecting on their dynamic work practices, together, and deducing principles from them for future, more effective activity.
Exnovation	The attempt to reveal and enhance what is already present (although sometimes hidden or taken-for-granted) in specific practices.

Hand hygiene	A general term applying to processes aiming to reduce the number of microorganisms on hands.
Healthcare associated infections (HAI)	Infections that are acquired in healthcare facilities or that occur as a result of healthcare interventions.
Healthcare workers	All people delivering healthcare services, including students and trainees, who have contact with patients or with blood or body substances.
Infection	The invasion and reproduction of disease-causing organisms inside the body that may cause tissue injury and disease.
Infection prevention and control (IPC)	A discipline concerned with preventing the transmission of communicable diseases in all health care settings.
Methicillin resistant <i>Staphylococcus aureus</i> (MRSA)	<i>Staphylococcus aureus</i> that has become resistant to certain antibiotics called beta-lactams. These antibiotics include methicillin and other more common antibiotics such as oxacillin, penicillin, and amoxicillin.
Multi-drug resistant organisms (MROs)	Microorganisms, predominantly bacteria, that are resistant to one or more classes of antimicrobial agents.
Personal protective equipment	Specialised clothing or equipment worn for protection against hazards, including gloves, gowns, bonnets, shoe covers, face shields, goggles and surgical masks.
Prevalence	The number of events (e.g. cases of disease) present in a defined population at one point in time.

Source-isolation	A strategy where isolated rooms are for the patients known or suspected to be infected with pathogens which can spread through the air, droplets or contact with others.
<i>Staphylococcus aureus</i> (<i>S. aureus</i>)	A bacterium that is frequently found in the human respiratory tract and on the skin.
Transmission-based precautions	Extra work practices in situations where standard precautions alone may be insufficient to prevent infection (e.g. for patients known or suspected to be infected or colonised with infectious agents that may not be contained with standard precautions alone).

Abstract

This thesis is an experiment in asking patients, their visitors, healthcare professionals and researchers to talk about things that are not generally addressed in healthcare services research to discover how we can move forward ‘together’ to improve patient safety. In particular, the people with the most at stake - the patients – are positioned as central to the conversation.

The conversations in this study are about healthcare-associated infections and infection prevention and control (IPC). Healthcare-associated infections, particularly those caused by multidrug-resistant organisms, represent an intractable issue causing significant, unnecessary suffering for patients and families and incurring escalating healthcare costs. Despite increasing standardisation and implementation of IPC strategies, healthcare-associated infections remain the most frequent adverse event experienced by patients worldwide. I argue that the less than optimal outcomes of current strategies for addressing healthcare-associated infection are in part a result of the failure to attend to the complexity of frontline work, and of an underestimation of patients’ roles in IPC.

In this research, I mobilised the interventionist methodology, video-reflexive ethnography, in new ways, to assist patients, clinicians and myself to explore the practical and relational complexities of patient involvement in IPC, and in healthcare-associated infection research. First, hospital inpatients were invited to scrutinise footage of their own clinical care to look for cross-contamination risks. The rationale for doing this was to acknowledge and respect patients’ expertise and contributions to their own safety, and to ascertain whether this approach could have a transformative impact on patients, as it has for clinicians in previous video-reflexive ethnography research. Group reflexive sessions were then conducted with

nurses in which footage of everyday patient care interactions *were presented alongside* patients' observations of the same events. The aim here was to explore whether such feedback might broaden nurses' understandings of infection risks and assist them to appreciate the productive possibilities of patient involvement.

Invoking complexity and affect theories as analytical tools, this research demonstrates that using video-reflexive ethnography in this novel way created a 'safe space' for everyone to reflect on and reshape their assumptions, positions and practices: for the patients who developed a more critical attitude to infection risks and were able to develop new strategies for getting their infection prevention needs met; for the nurses whose often taken-for-granted practices were disrupted by seeing care through their own patients' eyes and were therefore enabled to consider patients as active participants in infection prevention; and for me who, by considering myself a research participant, was able to come to new understandings about my own infection control and research practices. The findings show that patients were actively contributing to IPC in ways that clinicians and researchers were not fully aware of. Some of the strategies were effective and some were counterproductive. Engaging with these contributions enabled the clinicians to understand how the quality of their patient-provider relationships and IPC conversations shaped patients' attentions and precautions around infection risks and behaviours and motivated clinicians to develop strategies to promote greater patient involvement.

Two main conclusions emerge from this research. First, that patient involvement is an interpersonal, affective dynamic; the quality of which can strongly influence IPC behaviours. Second, that video footage can provide an important springboard for revealing and grappling with this affective dynamic. Viewing footage of their real-time care practices, in conjunction with patients' feedback on this care, can shrink the patient/clinician feedback loop: enabling

clinicians to better understand how their own views about what constitutes good IPC aligns with the views of patients under their care; how mismatches between the two can impact upon patient safety issues like healthcare-associated infection; and to reflect on what could be done differently. Here, the importance of employing video footage is that it elicits more from patients than just memories and opinions about care. Rather, it allows patients to refer to specific aspects of care practices and relationships that clinicians can then focus on with an eye to practice change. Instead of calling for more standardised IPC strategies, we must ensure that all stakeholders be afforded the time and space to collaboratively examine the complexity of their *in situ* infection control activities, relationships and habituations so that *together* they can tackle the problem of healthcare-associated infection.

Chapter One Introduction

My grandmother lay in a bed in the emergency department. She wore a white gown that had fallen from her shoulder revealing her thin, frail arm, bent at the elbow so she could support her head in her hand. I could see the ECG leads attached to her chest that was rising and falling rapidly as she laboured to breathe. Her eyes were closed but she opened them as I ran my hand over her hair and kissed her forehead. White, filmy eyes looked at me but without recognition. "I feel so sick." she said and closed her eyes again. Her nurse, Freda, smiled at me.

Another nurse arrived moving quickly and with purpose. The ED was busy. She was holding two uncapped medication syringes in her already gloved hands. She waved the syringes around as she explained something to Freda. I was worried that she had not washed her hands before putting on the gloves and worried about what the uncapped syringes might have touched on their way from wherever they were prepared. She did not acknowledge me as she unscrewed a red cap from the intravenous line in my grandmother's arm and began to attach the first syringe. I was surprised that there was no inline injection port that could be swabbed with alcohol before attaching the syringe. She pushed the medication through the line that directly accessed my grandmother's blood stream, pushing any microbes from the tip of the syringe along with it. I noticed that she had placed the red cap in the palm of her unsterile glove and I realised with alarm that she was probably going to put the dirty cap back on the line. Any bacteria on the dirty cap could cause a bloodstream infection, many of which are fatal. "Say something," I screamed at myself silently. "Tell her to get a new cap." But I stood frozen, unable to say anything.

What happened here in terms of patient safety? For me many questions were raised around rules, guidelines, role and background. What are the guidelines? Why were the guidelines not followed? What is my role as a patient's relative? What is my role as an "off duty" nurse?

Questions also arose around emotions, feelings, personalities and positions. Why could I not speak up to this nurse? Was it the way she looked? The way she acted? That she reminded me of someone who in the past had treated me dismissively? If I made a fuss, would it create conflict between the nursing staff and me? What could the potential consequences be for my grandma if I did speak up? How might it affect her care?

This research is an experiment in having people ask and explore these kinds of questions with me and with each other. It is an experiment in getting patients, families, healthcare professionals and researchers to talk about things that are not generally addressed in healthcare and, in doing so, discovering how we can move forward 'together' to improve patient safety. In particular this research positions the people with the most at stake - the patients - as central to the conversation.

1.1 Background

In this thesis the conversations are about healthcare-associated infections (HAI) and infection prevention and control (IPC). Each year hundreds of millions of patients worldwide are affected by potentially preventable HAI, causing patients needless pain and suffering, prolonged hospital stays, financial burden and even death (World Health Organization [WHO], 2011). The overuse and misuse of antibiotics has resulted in multidrug-resistant organisms (MROs) that further increase the morbidity and mortality associated with infections (WHO, 2012b). The main approach to reducing HAI has been the development, by infection control experts, of evidence-based, standardised IPC rules and guidelines;

promotion of these rules through education; and regular monitoring, auditing and public reporting of infection rates and service compliance with established guidelines (Siegel, Rhinehart, Jackson & Chiarello 2007). Here, the emphasis is on eliminating error by standardising behaviours and filling knowledge gaps.

This is well exemplified in the “My 5 Moments for Hand Hygiene” guidelines that were developed to provide key moments when health-care workers should clean their hands (Sax et al., 2007; WHO, 2009) (see appendix A). These moments are presented to frontline healthcare professionals who are then monitored and audited for compliance. Hand hygiene is cited as the most effective measure for reducing infection transmission (Grayson, Russo, Ryan, Havers, & Heard, 2013; WHO, 2009); yet, despite wide-spread promotion and global uptake of the ‘5 Moments’, most hospitals in Australia are performing below the national hand hygiene compliance threshold (Azim & McLaws, 2014), the average hand hygiene compliance rate in industrialised countries sits at around 40% (Erasmus et al., 2010), and HAI remains the most frequent adverse event experienced by patients worldwide (WHO, 2011).

In this thesis, I argue that current strategies fall short of their potential because HAI is a wicked problem¹ that cannot be fully addressed by reliance on linear, idealised models of

¹ Many years ago Rittel and Webber (1973) coined the term “wicked problems” for societal problems that are inherently ill-defined. “They rely on elusive political judgment for resolution. (Not ‘solution’. Societal problems are never solved. At best they are only re-solved – over and over again)” (p.160). More recently, Van Woezik et al., (2016) suggest that IPC can be seen as a wicked public health problem due to a lack of consensus by the various stakeholders, who often harbour profoundly different values, needs and views, for understanding and problem-solving infection transmission (van Woezik, Braakman-Jansen, Kulyk, Siemons, & van Gemert-Pijnen, 2016). With the added complication of antimicrobial resistance, HAI can even be considered to be a “super wicked challenge” (Kessel & Sharland, 2013; McLellan et al., 2016). Levin et al., (2007) explain that with super wicked problems there is a sense that: time is running out; that no central authority has yet been effective in adequately addressing the problem; that many who seek to end the problem are contributing to it and; that even in the face of overwhelming evidence, people disregard the potential future impact. With the emergence and rapid spread of multiple-drug resistant organisms and the lack of urgent corrective and protective actions taken by stakeholders at every level, the world looks on the cusp of a post-antibiotic era (Chan, 2011; Walsh, 2013).

practice such as the 5 moments. This thesis suggests that more attention must be paid to how these rules and guidelines play out in complex local settings and argues for a greater recognition of frontline actors as a “critical source of insight and momentum for dealing with the rising levels of complexity of care” (Iedema, Mesman, & Carroll, 2013, p. 1). This includes acknowledging, exploring, accepting and engaging with the roles that patients and their visitors play in identifying infection risk and preventing cross-contamination (Hor, Godbold, Collier, & Iedema, 2013; Wyer, Iedema, & Hor, 2014).

I further argue that IPC conversations between clinicians and patients (as well as between clinicians themselves) are crucial for accommodating healthcare complexity and assisting in the reduction of HAI. Moreover, I contend that in privileging the technical and cognitive aspects of IPC, healthcare policymakers, clinicians and researchers have neglected how people’s feelings, personalities and emotions affect the way in which IPC is performed in the moment-to-moment of care interactions. Thus the notion that “affect undergirds how and whether people act” (Iedema, Jorm, & Lum, 2009, p. 1755) is central to this thesis.

This notion extended into how I approached my own role in this research. I actively sought to affect, and to allow myself to be affected by, the many collaborative relationships I formed during this research so that together we could “grasp and deal with complexity and emergence *in situ*, to discover new ways of being” (Collier & Wyer, 2016, p. 981). These collaborative relationships were formed with consenting participants/co-researchers as well as the many co-authors of the four published papers that are embedded in chapters 4 to 7 in this thesis and which are detailed in the next section.

1.2 Overview of the thesis

This research is undertaken as part of a wider National Health and Medical Research Council (NHMRC) funded project entitled ‘Strengthening frontline clinicians’ infection control: A multi-method study to reduce MRSA² infection and transmission’³. This project was conducted in conjunction with another NHMRC-funded project, ‘Microevolution and Transmission of MRSA in a hospital setting’⁴. Together, these projects sought to lower MRSA transmission rates by engaging and intervening in the infection control beliefs, habits and routines of front-line clinicians as they provided care, using video-reflexive ethnography, and by providing clinicians with rapid feedback of highly specific MRSA transmission and hand hygiene audit data for their wards.

Video-reflexive ethnography (VRE) is an interventionist methodology that involves videoing care processes and then showing the video back to those in the footage, and to their colleagues, to “foreground experience and its complexity” (Iedema, Mesman, et al., 2013) and to initiate discussions that can elicit and institute alternatives to deal with “problematic aspects of their work” (Iedema, Long, Forsyth, & Lee, 2006, p. 159).

When I joined the project team I was asked to develop a PhD research project that would complement the video research. I was able to develop my own aims, research questions and research design. I considered and then decided against several ideas. It was when I visited one of the fieldwork sites for the wider project that I became more sensitive to the realisation that patient participation in this project was limited to being videoed during care episodes.

The resulting footage would only be shown back to clinicians for making sense of IPC

² Methicillin resistant *Staphylococcus aureus* (MRSA) is a mutation of *Staphylococcus aureus* that has become resistant to certain antibiotics called beta-lactams. These antibiotics include methicillin and other more common antibiotics such as oxacillin, penicillin, and amoxicillin.

³ NHMRC funded project #1009178

⁴ NHMRC funded project #1010452

practices. I believed that without patients' insights and involvement, the NHMRC project would fail to attend to the full complexity of IPC. After all, patients have the most at stake when it comes to HAI and, in my experience as a nurse, they are rarely passive subjects upon whom the rituals of IPC are played out⁵. In my experience, patients move about, sit on each other's beds, share personal items and use communal spaces with other patients. Visitors do the same. Patients who are colonised and infected with MROs leave their isolation rooms for therapies, diagnostic tests and to relieve their boredom. Visitors enter and exit isolation rooms with varying adherence to isolation precautions.

Around this time I was also introduced to YouTube clips being made by a young man who spent six months in source-isolation⁶ after he acquired multidrug-resistant tuberculosis. Under the nickname 'The Fully Sick Rapper' he posted humorous songs and accompanying video clips by which he attempted to make sense of his medical situation⁷. Watching these clips I noticed the significant work he undertook to prevent transmission and raise awareness about tuberculosis: adhering to medication regimes and quarantine; seeking information about his condition; educating visitors on protective behaviours; and promoting public awareness of tuberculosis prevention and treatment for the World Health Organization. On this background, I decided that the contribution of my PhD research could be to promote a more central position for patients in the research in a way that would respect their opinions, expertise and contributions to IPC.

In Chapter 2, I locate the study theoretically against a background of research on patient safety generally and HAI specifically, addressing conventional understandings and

⁵ Unconscious patients perhaps being the exception.

⁶ "The term source-isolation is used to define the steps that are implemented to prevent the spread of an infectious agent from an infected or colonized person (i.e. the source) to another person (i.e. the host)" (Gammon, 1999, p. 14).

⁷ See this link for the story of The Fully Sick Rapper as well as his videos:
<http://blogs.msf.org/en/patients/blogs/tb-me/the-story-of-the-fully-sick-rapper>

approaches to both. I discuss how these approaches, in their privileging of formal knowledge and individual human cognition, ignore the complex circumstances in which clinicians and patients often find themselves. I make a case for a complementary paradigm of patient safety research; one that shifts from an emphasis on top-down, prefigured and knowledge-based solutions, to one that includes co-generating safety awareness with frontline actors at the point of care.

I then argue that patients and families are frontline actors actively involved in producing safety. I discuss some of the key debates surrounding the emerging field of patient involvement in patient safety, including calls by international bodies such as INVOLVE (2012) and PCORI (Ellis & Kass, 2016) for more active patient involvement in research.

Finally, I present a literature review on HAI and IPC research that has involved patients. I discuss some of the core findings from this body of research, but mainly interrogate the methodologies used to involve patients. I argue that the bulk of these studies used methods that are distanced from the complexity of everyday care and that privilege the role of the researcher and/or clinicians. I conclude that there is considerable opportunity for more participatory methodologies that award primacy to patient expertise and agency.

In Chapter 3, I describe how I experimented with VRE to create new ways of involving both patients and clinicians in IPC research. I begin this chapter by positioning myself in the research, describing the personal and professional experiences that I brought to the study. I then provide an overview of the VRE methodology, including its philosophical and theoretical underpinnings. Following this, I outline the methods I used in this study including ethnographic field observations, field interviews, unstructured interviews, video ethnography and video-reflexivity. The prominence of each of these methods varied throughout the research. However, particular emphasis was placed on using video-reflexive methods to

foster relationships that would enable patients⁸, clinicians and myself to explore the practical and relational complexities of patient involvement in IPC and in IPC research. This emphasis was based on my belief that engaging clinicians and patients in discussing complex clinical care issues is critical for gaining traction with what might otherwise seem to be intractable safety problems like HAI. Although one of the main aims for my research was to explore new ways of using VRE, I did not want to exclude patients who did not wish to be videoed. Therefore, participants were offered a range of options for involvement and were also encouraged to offer their own suggestions.

Chapter 4 presents the methodological findings of the research. This is presented as a published paper written with Dr Aileen Collier who uses VRE to explore end-of-life care with patients. This paper presents and analyses the opportunities and challenges that we encountered (in our respective PhD projects) when collaboratively researching with patients using VRE. We found that the progress and success of our studies were critically dependent on our multi-layered, iterative researcher reflexivity as researchers in the field. The manuscript titled 'Researching reflexively with patients and families: Two studies using video-reflexive ethnography to collaborate with patients and families in patient safety research', has been published in *Qualitative Health Research* (2016), 26(7), 979-993.

Chapters 5,6 and 7 contain the empirical findings of the thesis. Each of these chapters is presented as a published paper. I sought to publish in a range of journals and each differed in its guidelines for style, structure and content. Due to specific journal requirements, there is some repetition of literature cited, theory, methodology and methods. I wrote with a diversity of authors, including patients, nursing and medical academics, and social scientists. As I

⁸ The experiences and expertise of both patients and their families/visitors were sought in this research. Despite many attempts very few family members/visitors consented to participate. Therefore from this point on, unless specifically indicating family/visitors, I will refer to 'patients' only.

mentioned earlier, not all patients wished to be videoed, and Chapter 5 gives prominence to the voices of these participants. Drawing mainly on ethnographic observations and field interviews this chapter sets the scene for how one particular IPC practice, namely source-isolation for MROs, was enacted in this particular unit. The bulk of patient-experience literature on this topic focuses on the adverse physical and psychological impacts of source-isolation on patients. In contrast, this paper discusses how a lack of clinician/patient dialogue around source-isolation practices resulted in patient and visitor activities that may have contributed to the high levels of MRO transmission on this ward. This paper argues that the effectiveness of IPC measures will be sub-optimal unless researchers and clinicians pay attention to the activities of all patients and their visitors and engage with them as active partners in reducing MRO transmission. This manuscript titled ‘Should I stay or should I go? Patient understandings of and responses to source-isolation practices’, is published in *Patient Experience Journal*, (2015), 2(2), 60-68.

Chapter 6 takes a look at what is made possible when patients are invited to take a more active and central role in research around IPC. In this paper, the patients and I continue to explore patients’ experiences of IPC as well as the possibilities of patient contributions for HAI reduction. The novel contribution of this paper is the unprecedented use of VRE to invite patients to scrutinise footage of their own clinical care for infection transmission risks. I discuss how this process supported patients to come to better understandings of IPC practice and how they may better position themselves in these practices.

In Chapter 7, I describe how I extended VRE methodology by presenting footage of clinical care interactions, in conjunction with patient analyses of the same interactions, to the nurses who cared for these patients. I describe how this application of VRE created an affective space that enabled new ways for the nurses to relate to patients in their care. Shrinking the

patient/clinician feedback loop broadened the nurses' understandings of local IPC risks and assisted them to appreciate the productive possibilities of patient involvement in IPC.

In Chapter 8, I summarise the key findings of the research as they relate to each of my research questions. I demonstrate my contributions to the patient involvement and HAI/IPC literature, as well as to VRE methodology. I also examine the strengths and limitations of my research and potential avenues for future research.

Chapter Two Literature Review

2.1 Introduction

This chapter provides the context for the study by providing a background to the research, issues and debates around patient safety and patient involvement in safety. I first expand on the significance of healthcare-associated infections (HAI) as a patient safety issue. Next, I present the prevailing methods for addressing patient safety generally, and HAI in particular, and discuss some of the limitations of these approaches. I then examine literature that offers a new paradigm for patient safety research: one that pays more attention to the complexity of care in the here-and-now and recognises the expertise of frontline actors. Finally, I discuss the role of patients in safety and safety improvement research and provide a short review of the HAI/IPC literature that has involved patients.

2.2 HAI is a major patient safety issue

HAIs are infections acquired by patients when receiving care in a hospital or other healthcare facility. They affect hundreds of millions of patients worldwide (WHO, 2011). Each year, Australian healthcare facilities are responsible and estimated 180,000 potentially preventable HAIs that cause patients' pain, prolonged hospital stays, and death as well as generating financial burden for patients, families and healthcare facilities (Australian Commission on Safety and Quality in Health Care [ACSQHC], August 29, 2012). In Europe, around 4.1 million patients are affected by HAI per annum (WHO, 2011). In 2011, 721,800 HAIs were acquired in U.S. acute hospitals (Magill et al., 2014) and as a result of this an estimated 75,000 patients died during their hospitalisation (Centers for Disease Control and Prevention [CDC], 2016).

Further impacting on the morbidity and mortality associated with HAI is the increasing problem of antimicrobial resistance, which has been caused by use and misuse of antibiotics

for humans and animals, as well as in agriculture (WHO, 2015). World health leaders are taking antimicrobial resistance very seriously. The chief medical officer in the United Kingdom Dame Sally Davies, has warned that the rapid emergence of drug resistant diseases poses an ‘apocalyptic’ threat that could trigger a national emergency (Sample, 2013).

Margaret Chan, Director-general of WHO, cautioned that the world is heading toward a post-antibiotic era unless we take urgent corrective and protective action, declaring that the world has collectively failed to appropriately handle the “miracle cure” of antibiotics, through a "number of human practices, behaviours, and policy failures” (Chan, 2011). A recent United Nations general assembly has responded by pledging a coordinated global effort to address the root causes of antimicrobial resistance (General Assembly of the United Nations, 2016).

Antimicrobial resistance is particularly likely to develop and spread in hospitals (WHO, 2012b). *Staphylococcus aureus* (*S. aureus*) is a common bacterium carried by many healthy people on the surface their skin or in their nose, and is usually harmless unless it enters the body and multiplies. Methicillin resistant *S. aureus* (MRSA) is a form of *S. aureus* that has developed resistance to numerous antibiotics to which it was previously susceptible and emerged as one of the predominant pathogens causing HAI. It is often used as a marker for the quality of a facility’s IPC program, because it is predominantly spread from person to person by direct or indirect contact, often on the hands (Borg, Camilleri, & Waisfisz, 2012; Voss, Kluytmans, & Pittet, 2012). MRSA often impacts on already vulnerable patients: the chronically ill, immunosuppressed and those undergoing surgical procedures or insertion of invasive lines (Ferguson, 2009; Romero, Treston, & O'Sullivan, 2006). Treatment options are limited, resulting in greater risk of complications and death (Cosgrove et al., 2003). In the United States alone, “more than two million people are sickened every year with antibiotic-resistant infections, with at least 23,000 dying as a result” (CDC, 2013, p. 6). Other dangerous and resistant pathogens have emerged with increasing frequency over the past

several decades including: vancomycin resistant *enterococci*; multi-drug resistant *Clostridium difficile*; extended spectrum β -lactamase-producing and carbapenem resistant Enterobacteriaceae; and multi-resistant *Acinetobacter baumannii* and *Pseudomonas aeruginosa* (Fair & Tor, 2014).

Because transmission of infections in hospitals occurs through direct or indirect contact during patient care, largely on the hands of clinicians and other healthcare workers, most HAIs are potentially preventable through good hand hygiene practices (Ferguson, 2009; WHO, 2009). Yet, despite the increasing standardisation and global implementation of infection prevention and control strategies, such as the ‘5 moments for hand hygiene’, HAI is a “problem that no institution or country can claim to have solved yet” and it remains a significant and pressing patient safety issue (WHO, 2011, p. 8).

2.3 Approaches to Patient Safety

Patient safety is a comparatively new healthcare discipline. It has risen to prominence with a growing awareness of the harm to patients that can occur as a result of healthcare (The Health Foundation, 2013). Although studies on iatrogenic harm⁹ have been reported since the 1970s, it was not until 1999, when the Institute of Medicine targeted the general public with its first report *To Err is Human* (Kohn, Corrigan, & Donaldson, 2000), that patient safety debate and action widened (Elwyn & Corrigan, 2005). Since then considerable efforts have been made to improve the safety of healthcare (Vincent & Amalberti, 2016) although some suggest that only modest improvements have been made thus far (Hollnagel, Wears, & Braithwaite, 2015; Wachter, 2010).

⁹ Iatrogenic harm is “avoidable harm caused by the process of healthcare itself, rather than by an underlying injury or disease” (Runciman, Merry, & Walton, 2007, p. 1)

In their recent book Vincent and Amalberti (2016) identify three main historical phases for patient safety approaches, each associated with different types of action and intervention (p. 72-75). The period between 1995 and 2002 focused on establishing reporting systems that could detect and record incidents, with the ultimate aim of preventing them. Here, safety is measured retrospectively in an effort to find out why harm occurred (O'Hara & Isden, 2013). Following this, between 2002 and 2005, concepts from industrial safety were applied to healthcare and increasing attention given to improving systems through human factors and process engineering approaches. A greater focus on safety culture and teamwork, followed between 2005 and 2011. It has also been increasingly recognised that the rising complexity of health care is an underlying factor for adverse patient safety events (Dekker, Cilliers, & Hofmeyr, 2011). Since then, the main response to this complexity has been attempts to reduce or eliminate it through increased standardisation and there has been an exponential rise in the development, by 'experts', of rules, checklists and guidelines, based on latest evidence-based knowledge, to define and measure how clinicians carry out safety critical tasks. The two principal objectives of this top-down approach are "the simplification of clinical work and the alignment of individual professionals' knowledge, actions and intentions to formal rules" (Hor & Iedema, 2015, p. 669). When it comes to addressing HAI, the approaches favoured to reduce infections have similarly privileged rules as the prime means for intervening in clinicians' conduct.

2.4 Current approaches to reducing HAI

In Chapter 1, I briefly outlined one of the major global strategies for reducing HAI: The '5 moments of hand hygiene' (Sax et al., 2007). The WHO has adopted this strategy as part of its multimodal approach to improve hand hygiene in global healthcare settings. This approach includes five essential elements: systems change (to ensure healthcare workers have access to hand hygiene facilities); regular education on the '5 moments for hand hygiene'; evaluation

and feedback on hand hygiene compliance; reminders for hand hygiene in the workplace and; a safety climate that raises awareness of HAI and hand hygiene (WHO, 2009, p. 96). This aligns with the ‘simplification and alignment’ approach described in the previous paragraph. Here, HAI is delineated as largely a problem of hand hygiene compliance that can be solved or tamed through simplified, linear rules and education. These strategies have their place and can work well in controlled environments, but they also have their limits. The 5 moments, for example, are described as an “evidence-based, field-tested, user-centred approach [that] is designed to be easy to learn, logical and applicable in a wide range of settings” (WHO, 2017). Despite this, clinicians continue to have highly variable behaviours and attitudes around hand hygiene practices, which have contributed to suboptimal compliance as well as challenging the sustained success of the approach (Pittet et al., 2004; Stewardson et al., 2016). Furthermore, observing and reporting hand hygiene is open to multiple biases (Joint Commission, 2009), and recent research shows that more intense hand hygiene practices rarely correspond in straightforward ways with lower HAI rates (Azim & McLaws, 2014; Marimuthu, Pittet, & Harbarth, 2014). This body of research suggests that our assumptions about what works in IPC may be out of step with the reality and scope of infection risk, notwithstanding the rigour and evidence invested in our guidelines.

Other approaches to reduce acquisition and transmission of MROs in hospital include: antibiotic stewardship, surveillance and reporting of infections, appropriate environmental cleaning, aseptic technique for invasive procedures, the use of personal protective equipment, and standard and transmission based precautions (NHMRC, 2010), including source-isolation which is particularly pertinent to this thesis. In hospitals, transmission precautions are implemented for patients who have communicable diseases or are identified as infected or colonised with MROs – to prevent transmission via direct or indirect contact with the patient or the patient’s environment. The CDC recommends that: patients be placed in source-

isolation, either in single rooms (when available) or cohorted with patients who have similar MROs; staff use personal protective equipment, such as gloves and gowns, when inside source-isolation rooms; staff use dedicated or disposable patient care equipment where possible; cleaning and disinfection of equipment between patients when common use is unavoidable; and frequent cleaning is carried out in source–isolation rooms (Siegel et al., 2007).

Debates around the efficacy of source-isolation suggest that the clarity of these guidelines does not always translate to clear outcomes. One CDC literature review reports significant HAI reductions found in several studies, but it concedes that there are several factors limiting the ability to generalise the results (Siegel et al., 2007). Other studies have found no effect after implementing active surveillance and/or expanded contact precautions (De Angelis et al., 2014; Huskins et al., 2011; Kho et al., 2008). Furthermore, a number of studies have measured staff compliance with source-isolation rules, usually using survey and covert staff observation methods, and have found inadequate adherence to guidelines (Clock, Cohen, Behta, Ross, & Larson, 2010; Franca et al., 2013; Jessee & Mion, 2013; Morgan et al., 2013). Despite growing concern and conflicting data from studies investigating the effectiveness of these interventions, recommendations still focus on improving components of contact and source-isolation precautions through identifying and rectifying non-adherent practices (Cohen, Cohen, & Shang, 2015).

For their part, Morgan *et al.* (Morgan, Kaye, & Diekema, 2014) state there is “little evidence that [source-isolation measures] prevent MRSA [...] infections in endemic, non-outbreak settings” (p. 1395). They suggest that improved use of standard precautions (most commonly hand hygiene) may be a better alternative, implying that a simpler set of rules, requiring less training and easier monitoring of compliance, may have a greater effect on transmission

reduction. There are other researchers who recognise that knowledge does not necessarily predict IPC behaviours (Allen & Cronin, 2012; Pittet et al., 2004). They suggest that ‘social cognitive models’ be deployed to the cause of raising clinician compliance with IPC rules. These models posit individuals’ attitudes, beliefs and personal traits to be the principal determinants of their in-clinic behaviours.

The common thread weaving through all these endeavours and their recommendations is this: privileging individual human cognition in the forms of both knowledge and motivation as the mainspring(s) of optimal infection control. Accordingly, these endeavours aim to ensure that clinicians ‘know what to do’, and to amend any resistance or avoidance in line with the rules of IPC. This privileging of individuals’ cognitive capacities, however, ignores the complex circumstances in which clinicians and patients often find themselves. General knowledge and personal motivations might not be commensurable with emergent complexities such as competing clinical demands, patients’ intricate service trajectories, different staff’s priorities and concerns, the unclear nature of infection risk, and the diffuse and deferred impacts of actual infection (Iedema et al., 2015). Rather than relying solely on the knowledge/evidence approach to dealing with infection risk, we need to tease out the implications of what it means for clinicians and patients to have to compose and orchestrate IPC conduct amidst high levels of complexity.

2.5 Complexity thinking

Complexity thinking has been mobilised by some researchers to provide concepts and tools to assist in responding to complexity in healthcare (Carroll, 2009b; Fraser & Greenhalgh, 2001;

Plsek & Greenhalgh, 2001). Complexity thinking finds its inspiration in complexity theory¹⁰, which helps us to appreciate the multiple variables and emergent phenomena that result in unexpected and unpredictable events despite our best efforts to tame our existence through research, the pursuit of knowledge, proceduralisation and standardisation (Kernick, 2006). Consider, for instance, the ‘knowledge of rules’ approach to patient safety, which adheres to the promise of “neat packages of knowledge and a universal language that can apparently be easily transferred between any context” (Richardson & Cilliers, 2001, p. 7). Complexity thinking challenges this line of thinking in two ways. The first is by pointing out the “limits of our knowledge in light of complexity” (p.7). Knowledge is by definition of things *past*, and is unable to account for all events happening in the present. This is despite the fact that, in our fast-paced, contemporary world, there is so much knowledge that we “risk drowning in it” (Fraser & Greenhalgh, 2001, p. 800).

Indeed, the proliferation of knowledge (i.e. the attempt to account for emerging events and circumstances) adds to contemporary complexity (Dekker, 2011). Evidence, standards and guidelines are issued at an increasing rate. Yet there is evidence that this plethora of evidence, standards and guidelines has an unintended and paradoxical effect: staff may not necessarily know these resources exist or how to access them (Cicolini et al., 2014; Lupion-Mendoza, Antunez-Dominguez, Gonzalez-Fernandez, Romero-Brioso, & Rodriguez-Bano, 2015). Likewise, new rules may replace old ones but the process of integrating the new ones into practice may not keep pace with rule production, leaving frontline staff none-the-wiser (Clack, Kuster, Giger, Giuliani, & Sax, 2014). What further renders frontline staff reluctant to

¹⁰ Complexity science is a vast and evolving field of study that has emerged across a broad range of disciplines, as wide ranging as finance, computers and sociology, to study complex systems (Kahlen, Flumerfelt, & Alves, 2017; Kernick, 2006; Richardson & Cilliers, 2001). In this thesis, I draw on only a few complexity principles that have been used by some researchers to examine complexity in healthcare and health services research.

seek out new knowledge is that formal knowledge is often superseded soon after it is produced (Olsen, Aisner, & McGinnis, 2007).

Complexity thinking asks us to acknowledge and accept the incomplete nature of our knowledge *as we engage in everyday practice* (Carroll, 2009b; Richardson & Cilliers, 2001). It is no longer feasible that any one individual can accumulate, retain or rely on a rapidly increasing and changing body of knowledge. Likewise, it is not purely extant knowledge but an entirely different set of resources that is required to deal with many of the complex and unpredictable challenges that arise in care, including infection risks (Dekker, 2012).

Another aspect of complexity thinking relevant to patient safety and IPC research is the appreciation of the need for a deep understanding of context (Richardson & Cilliers, 2001). Relying wholesale on formal knowledge and pre-figured solutions for IPC neglects local contextual factors that can be crucial to the success or failure of the intended outcomes (Dixon-Woods, Leslie, Tarrant, & Bion, 2013; Zimmerman et al., 2013). Furthermore, in acknowledging the need for context-specific action, the constantly changing nature of the context itself must also be recognised (Hollnagel et al., 2015). If we accept that uncertainty, unpredictability and paradox are inherent in the application of rules and the delivery of care, and that knowing everything in complex circumstances is an impossibility, then we also acknowledge the need for a new paradigm to underpin patient safety and practice improvement in general and infection control specifically. This paradigm embodies a shift from top-down prefigured and knowledge-based solutions, to solutions that are tailored *in situ*, by frontline actors to deal with the complex circumstances in which they find themselves.

2.6 A complementary paradigm in healthcare improvement research

The methodological significance of the rise in complexity for how we investigate and achieve progress in patient safety has only recently been acknowledged. There is growing realisation that the complexity of care hampers not only the translation of generalised research findings and ideal-type solutions into *in situ* plans for action, but also the *de jure* enactments of those plans. This raises questions about the wisdom of investing all our resources in approaches oriented to producing ideal-world solutions, or what Vincent and Amalberti (2016) refer to as ‘optimizing strategies’. It is also argued that traditionally favoured research methods used in patient safety research are too distanced from the *in situ* complexity of frontline care to have sufficient relevance for that care. This has led advocates to emphasise the need for greater engagement with the ‘real world’ challenges that clinicians and patients face (Iedema, Mesman, et al., 2013; Vincent & Amalberti, 2016).

A growing number of patient safety researchers are now drawing on the theoretical viewpoint that safety is the ongoing practical accomplishment of frontline actors who constantly and contingently negotiate a multiplicity of ‘safeties’ in their daily activities (Hor, 2011; Hor et al., 2010; Iedema, Mesman, et al., 2013; Mesman, 2011). This negotiating and balancing of multiple safeties “highlight[s] the importance of attending to ongoing clinician-patient interactions as sites of safety production in complex health-care systems” (Hor et al., 2013, p. 568). Shifting our thinking from relying on pre-established knowledge to negotiating solutions in the here-and-now, and from a unitary conception of safety to a constant trade-off among multiple safeties, means connecting with the real-world challenges faced among clinicians and patients.

To a degree, this also shifts our thinking from associating safety with things that go wrong, to a greater attention to how things go right and how ‘right’ happens (Hollnagel, 2014; Hollnagel et al., 2015; Mesman, 2011).

We should not ignore the lessons we can learn from what is already in place and goes right. For this reason, patient safety research should not only be focused on error analysis and its standardized solutions or resilience but should also include analyses with a focus on existing practical know-how (Mesman, 2011, pp. 77-78).

Hollnagel and colleagues have referred to the adaptive capacity of people to cope with complexity under pressure as *resilience* (Hollnagel, Woods, & Leveson, 2006), where “systems perform reliably because people are flexible and adaptive, rather than because the systems have been perfectly thought out and designed or because people do precisely what has been prescribed” (Hollnagel et al., 2015, p. 17). The focus thus shifts from humans as the source of error, to human creativity as a source of safety (Mesman, 2011).

It is critical at this point to acknowledge that the realisation of safety entails a constant trade-off of safeties through ongoing negotiation with stakeholders, little of which can be prefigured (Iedema, Mesman and Carroll 2013). At best, what can be said about this dynamic is that stakeholders need to be willing to communicate, to identify priorities, certainties as well as uncertainties, preferences and wicked problems. The outcomes of such *in situ* communication to address complexity may not be ‘ideal’, expected, or replicable (Iedema, Mesman and Carroll 2013). Given these considerations, the focus of research shifts towards the mapping and tracing of co-produced understandings about how to conduct oneself amidst complexity, including the trade-offs among competing viewpoints, imperatives, and safeties.

This shift in focus has sparked a movement towards more participatory and collaborative research approaches that seek to co-generate safety awareness (rather than absolute safety knowledge) with frontline actors at the point of care. Critical here are the distinctions between ‘research on’ and ‘research with’ on the one hand, and ‘knowledge of’ and ‘awareness about’ on the other hand. With regard to the former, collaborative research is ‘research with’. ‘Research with’ distances itself from traditional top down approaches to patient safety research which seek to maintain an ‘objective’ distance between the ‘the researched’ and the ‘expert researcher’ (Iedema, 2011c). ‘Research with’ approaches recognise the expertise of frontline actors as critical to safety. One recent instance of this new paradigm is the United States’ Institute of Medicine’s *Learning healthcare system* framework. This framework calls for researchers working closely with those at the frontline, blurring the boundaries between clinical practice and research in order to “continuously generate, utilize, and disseminate generalizable knowledge in the service of improved quality, value, and innovation” (Psek et al., 2015, p. 1). In the United Kingdom, the National Health Service (NHS) is exploring a model that shifts power to clinicians and patients, and places more emphasis on learning in workplace situations.

A further shift going forward in health and care improvement will be an increasing focus on tacit knowledge rather than explicit knowledge for change. It is tacit knowledge, or know-how, created by learning in action and experience that is the most valuable knowledge for improvement and is most likely to lead to breakthroughs in thinking and performance. The people holding the tacit knowledge, often in their heads, include front line staff, patient leaders and senior leaders (Bevan & Fairman, 2014, p. 30).

Bevan and Fairman (2014) concede that, “converting tacit knowledge into spreadable, effective, explicit knowledge is a very challenging task”, but that this kind of knowledge is likely to be “best developed and shared through dialogue, conversations and social relationships” (p.30).

By and large, research in health care, healthcare improvement and patient safety remains beholden to the production of formal scientific evidence, where evidence is considered to be reliable only when produced through trial-design studies. Evidence produced through non-trial studies tends to be regarded as less significant and less reliable (Shekelle, Pronovost, & Wachter, 2010). The question that is infrequently asked here, however, is whether ‘evidence’ should indeed play the role it is conventionally granted in pharmaceutical studies, or whether complexity demands that we conceive of an altogether different phenomenon for conceptualising what is needed to ensure that *in situ* conduct is effective and safe (Iedema, Mesman and Carroll 2013). This new phenomenon is constituted of extant knowledge, but also of less tangible things, such as actors’ capacity to balance extant knowledge with *in situ* imperatives, stakeholder views, (variable) resource availability, and substandard conditions, including wicked problems arising from persistent uncertainties, and ‘tragic choices’ arising from low probability of care success.

Acknowledging the constraints inherent in the reality of everyday complexity, some researchers have begun to explore different ways of doing safety research, shifting the emphasis from building knowledge to normalising learning. One such research practice is video-reflexive ethnography (VRE) undertaken by Iedema *et al.* (2015), Mesman (2016), Carroll, Iedema and Kerridge (2008) and Hor, Iedema and Manias (2014), among others. This body of VRE work involves clinicians and enables them to devise solutions to the safety challenges they face. Targeting IPC research specifically, Mesman (2016) has collaborated

with clinicians in a neonatal intensive care unit over many years working alongside them to understand how they produce safety in the moment-to-moment unfolding of their IPC practices. The methodological background to VRE, as well as the IPC project that this PhD study is nested within, are discussed in more depth in Chapter 3.

In summary, this new research paradigm frames safety as being produced in the here-and-now through the strengthening of *in situ* relationships and shared understandings, rather than being primarily contingent on the production of knowledge. This requires frontline actors to enhance their connectivity (Christakis & Fowler, 2009), requiring them to become smarter about ‘acting together’ and dealing with complexity in the here-and-now. In this literature, acting together is argued to be a powerful resource that emerges when researchers and frontline actors build networks, shared purpose, and collaborative practices (Iedema & Carroll, 2015). To achieve this, researchers cannot distance themselves from, or objectify those they wish to study. Instead they need to build emotional connections with them, through becoming more sensitive to the complexity and dynamics of everyday work and relationships (Iedema & Carroll, 2015).

Approaching IPC in this new paradigm means less focus on rule compliance, and more focus on actual *in situ* conduct. Thus, it involves researchers and frontline actors examining together how IPC is negotiated and enacted in complex and local environments. It also involves researchers and participants collectively exploring the strengths and opportunities for change relevant to the issues frontline people find most pressing (Crowe, Fenton, Hall, Cowan, & Chalmers, 2015). Finally, research has shown that patients and families are also frontline actors who are involved in producing safety, even though clinicians and researchers may not necessarily realise or acknowledge this (Hor et al., 2013). It is time that researchers

and clinicians engage with the ‘invisible’ work that patients perform to ensure effective IPC (Unruh & Pratt, 2007).

2.7 Patient involvement in safety and safety improvement research

The importance of patient involvement in the safety of their care is increasingly recognised and promoted (O'Hara et al., 2017; Schwappach, 2010; Vincent & Amalberti, 2016). There are some who argue that patients should not be expected to be involved *per se* (Entwistle, Mello, & Brennan, 2005; Lyons, 2007), that they may not want to be involved (Davis, Koutantji, & Vincent, 2008; Longtin et al., 2010), or that they are too often unable (because of their illness) to be involved in the safety of their care (Entwistle et al., 2005; Hill, 2011). However, a growing contingent of commentators contends that it is a moral imperative for healthcare providers to include those most at risk from harm (O'Hara & Isden, 2013; Schwappach, 2010; Sutton, Eborall, & Martin, 2014). Furthermore, some bioethicists go so far as to suggest that all stakeholders in healthcare services, including patients, have an ethical obligation to contribute to improvements in the quality and safety of healthcare (Faden et al., 2013).

Alongside these arguments is emerging evidence that when patients are actively involved in healthcare they achieve better healthcare outcomes and accrue lower healthcare costs (Dentzer, 2013; Hibbard & Greene, 2013; Hibbard, Greene, & Overton, 2013). Patients are present at all stages of care, across different facilities and disciplines, so they are eyewitness to the complexities of this care (Furniss, Iacovides, Lyons, Blandford, & Franklin, 2016; WHO, 2017; Zimmerman et al., 2013). As such, patients may be aware of errors that their clinicians do not see or have ‘learned not to see’ (O'Hara et al., 2017; Unruh & Pratt, 2007). Patients are also highly motivated to avoid harm and improve their own care outcomes (Berger, Flickinger, Pfoh, Martinez, & Dy, 2014; Weingart et al., 2005). There is further

substantial evidence that many patients are willing to partner with healthcare providers to prevent error (Longtin et al., 2010; McGuckin & Govednik, 2013), although their willingness depends on a number of factors including demographics (e.g. age, sex, education), the type of error targeted, and the action required by the patient (Sutton et al., 2014).

In high resource settings, the political imperative to involve patients has resulted in national programs that provide guidance and resources for all stakeholders. McGuckin and Govednik (2013) provide a timeline of some of these including: the “Patients and Families in Patient Safety: Nothing About Me Without Me” programme (National Patient Safety Foundation’s Patient and Family Advisory Council, 2003) and the “Guide to Patient and Family Engagement” (Agency for Healthcare Research and Quality, 2012) in the United States; the “Patients for Patient Safety” initiative (WHO, 2004, 2013) and “The WHO guidelines on hand hygiene in health care” (WHO, 2009) internationally; and in the United Kingdom, the “Patient Engagement in Patient Safety: A Framework for the NHS” (National Health Service [NHS], 2016). In Australia, the “National Safety and Quality Healthcare Standards” includes Standard two (“Partnering with Consumers”), which discusses systems and strategies for including consumers in the development and design of quality health care (ACSQHC, 2011).

Patient and public involvement in applied health research has also become more common in recent years with many funding bodies requiring it (Ives, Damery, & Redwod, 2013; Shippee et al., 2015). One argument is that active patient involvement can help to improve the quality of research and ensure more relevant outcomes for end users (Staley & Minogue, 2006).

In contrast to patient participation in their own safety, patient involvement in research focuses on helping to shape the research, e.g. prioritising research topics, informing how studies should be conducted, actually conducting data

gathering and analysis, and giving advice on how to conduct engagement

(Furniss et al., 2016, p. 2)

Frameworks developed by national advisory groups, such as INVOLVE¹¹ (2012) and PCORI¹² (2016, June), aim to support more active patient and public involvement in research. Researchers seeking to involve patients and public in research often draw on the INVOLVE model which outlines the different types of role that patients and the public can have:

- Participation - the traditional role of patients within research where they are the subject of research and provide data to be analysed.
- Involvement - lay people actively working with researchers to design, manage and/or conduct research, which can also include their active involvement in data gathering and/or data analysis.
- Engagement - the dissemination of research findings and their implications to patients and the public (INVOLVE, 2012, p. 7).

While respecting the importance of traditional ‘participation’ research, INVOLVE calls for more research that reflects ‘involvement’ through: *consultation* about research processes; *collaboration* through designing and undertaking research; or *user-controlled research*, which is “actively controlled, directed and managed by service users and service user

¹¹ INVOLVE is an organization funded by the U.K. Department of Health to promote and support public involvement in NHS, public health and social care research.

¹² Patient-Centered Outcomes Research Institute (PCORI) was established by the Patient Protection and Affordable Care Act. It “helps people make informed healthcare decisions, and improves healthcare delivery and outcomes, by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader healthcare community”(PCORI, 2014, October).

organisations” (p. 24). These approaches increasingly afford patients more decision-making power before, during and following the research.

These efforts notwithstanding, there has been little published research that offers patients a role in patient safety, either at an organisational level (Schiffinger, Latzke, & Steyrer, 2016; Sutton et al., 2014) or at the level of research (Furniss et al., 2016). Most published work in this area draws on patient safety reports (O'Hara et al., 2017) for which experts have designed satisfaction surveys (Al-Abri & Al-Balushi, 2014), patient-reported outcome measures (PROMs) (Nelson et al., 2015) and patient-reported experience measures (PREMs) (de Silva, 2013). Recently, a patient measure of safety tool (PMOS) was developed (Giles, Lawton, Din, & McEachan, 2013), providing an avenue for patients to identify “contributory factors to safety incidents” by asking patients to comment on safety factors as they occur around them when in healthcare facilities (O'Hara et al., 2016, p. 2). Several studies have demonstrated the acceptability and reliability of PMOS for obtaining patient feedback, and that patients can provide a unique perspective on safety (e.g. Hernan et al., 2016; Lawton et al., 2017; McEachan et al., 2014; Taylor et al., 2016). Concerns have been raised, however, that the abstract and decontextualized nature of PMOS (and other standardised tools) data might make it difficult to design tailored improvement programs (Iedema & Angell, 2015).

A recent study used PMOS data to engage staff in designing patient-centred safety programs (Lawton et al., 2017). The study involved collecting patient feedback through PMOS, as well as a patient incident reporting tool, and then presenting this data to staff in multidisciplinary action planning meetings. While patient participation was high, staff adherence to design plans based on patient feedback was low, and the authors were unable to demonstrate any overall effect of the intervention. In a related paper, the researchers explained that a number of factors must be in place for staff to make changes based on patient feedback (Sheard et al.,

2017). First, that staff must believe that patient feedback is worth listening to and acting on; second, that clinical teams require autonomy and the resources to act; and third, organisational support is often required for action plans to be realised. Thus, these researchers highlight that patient feedback in and of itself is often insufficient to drive improvements in practice, and that staff and organisational engagement with this feedback is also necessary.

Other than the studies mentioned thus far, there are few published studies specifically outlining interventions that encourage more active patient participation in safety *at the point of care itself*. A review by Berger et al. (2014) found only six studies that met the authors' inclusion criteria for effectiveness with a primary focus on patient engagement, and 12 studies that implemented patient engagement as an aspect of a broader patient safety program. Several of these were IPC initiatives and will be discussed in the next section.

2.8 Patient Involvement in HAI and IPC research and initiatives¹³

So how has the field of IPC responded to calls for greater patient involvement? My review of this literature finds that patients, family members and the public have been involved in hospital HAI/IPC research in three key ways:

- 1) Providing feedback about their knowledge and experiences of, and their attitudes to, HAI and IPC.
- 2) Participatory research studies investigating or implementing service change.
- 3) Being involved in interventions at the point of care to reduce HAI.¹⁴

¹³ Research studies where patients were merely surveyed for clinical or demographic data have not been included in this section.

¹⁴ See appendix B for a comprehensive list of research studies pertaining to each of these topics. In the text of this chapter, to avoid excessive listing of citations, I have chosen to reference specific research findings using systematic/literature reviews and/or a representative selection of articles spanning 1983-present.

Providing feedback

Providing feedback about their knowledge, experiences and attitudes of HAI and IPC, is the main way in which patients and the public have participated in hospital IPC research. This feedback has been collected through survey, interviews and focus groups. The main findings from this research are that: lay people have an awareness of HAI, but poor understandings of infection transmission (Burnett, Johnston, Kearney, Corlett, & MacGillivray, 2013; Gleeson, Larkin, & O'Sullivan, 2016; Gould, Drey, Millar, Wilks, & Chamney, 2009; Seale, Novytska, Gallard, & Kaur, 2015); they also have a general awareness of IPC strategies such as hand hygiene, the use of personal protective equipment, environmental cleaning and transmission precautions, although they have varying levels of understandings of the rules and rationale for implementing them (e.g. Istenes, Bingham, Hazelett, Fleming, & Kirk, 2013; Newton, Constable, & Senior, 2001; Pritchard & Hathaway, 1988; Sunkesula et al., 2015). A major and recurrent theme was that healthcare providers did not provide timely, adequate or accurate information to patients about HAI or IPC (Burnett et al., 2013), even after a patient had acquired an HAI (Barratt, Shaban, & Moyle, 2011; Gleeson et al., 2016; MacDonald, 2008). A qualitative metasynthesis of nine qualitative studies on patients' experiences of being source-isolated for MROs (spanning the period 1983 – 2010) demonstrated that although patients valued communication as the most important aspect of care it was the most underrated by health care providers (Mutsonziwa & Green, 2011).

Although individual responses to isolation were variable in these studies, recurrent themes emerged. With a few exceptions¹⁵, patients in source-isolation experienced more adverse safety outcomes than non-isolated patients, such as negative psychological effects (Guilley-Lerondeau, Bourigault, Guille des Buttes, Birgand, & Lepelletier, 2017; Lupion-Mendoza et

¹⁵ Exceptions include studies by Wassenberg, Severs and Bonten (2010) and Findik, Ozbas, Cavdar, Erkan and Topcu (2012) who found that short-term isolation for infection control does not influence patients' levels of anxiety, depression or quality of life.

al., 2015), less patient-clinician contact (Chittick et al., 2016; Jones, 2010; Morgan, Diekema, Sepkowitz, & Perencevich, 2009), delays in care or treatment (Morgan et al., 2009) and more non-infectious adverse events such as falls, pressure ulcers, and fluid/electrolyte disorders (Morgan et al., 2009). Patients also expressed a desire to be more involved in IPC but discussed barriers they perceived or experienced when attempting to engage with clinicians around the IPC practices. These included fears of offending and possibly undermining their relationship with clinicians (Michaelsen, Sanders, Zimmer, & Bump, 2013; Pittet et al., 2011; Waterman et al., 2006), and fear of reprisal (Ahmed Awaji & Al-Surimi, 2016; Longtin, Sax, Allegranzi, Hugonnet, & Pittet, 2009; Michaelsen et al., 2013).

It is not surprising that patients suffer, from acquiring hospital infections and being subjected to isolation practices. What is astonishing is how little progress has been made, over the years, in alleviating this suffering. Despite three decades of research, concluding that poor communication between clinicians and patients about HAI and IPC practices is the main contributing factor to adverse psychological effects experienced by patients, current education and communication strategies around HAI or IPC are *still* not meeting their informational needs (e.g. Chittick et al., 2016; Gleeson et al., 2016; Santiano, Caldwell, Ryan, Smuts, & Schmidt, 2014). Furthermore, after several decades of policy mandating that practitioners empower patients to become more involved in patient safety activities, patients are still reluctant to question or challenge healthcare workers about IPC practices (e.g. Flannigan, 2015; Michaelsen et al., 2013; Seale, Novytska, et al., 2015).

Therefore, despite the important insights that surveys, interviews and focus groups can yield, perhaps the lack of progress in this body of research also reflects their limits. First, these methods are located in the knowledge paradigm discussed earlier, where objective knowledge is accrued at several removes from the complexity of *in situ* care as it unfolds. Distanced in

time and space, these methods may not adequately account for the moment-to-moment emotional and practical aspects of patient/clinician interactions that impact on how patients understand and experience IPC (Iedema, Mesman, et al., 2013). Second, the literature on patients' willingness to be involved in interventions reports only on their intentions, which are known to correlate poorly with actual behaviour (Sheeran, 2002). Third, survey data, in particular, can offer a restricted set of pre-determined items that limit responses and prevent participants from sharing their own issues of concern (Gould et al., 2009; O'Hara et al., 2017). Interview and focus group methods offer more scope for subjective views. However, like surveys, these methods rely on a participants' memory and recall, which are not always accurate or dependable (Bradburn, Rips, & Shevell, 1987). Greatbatch *et al.* (2001) also point out that "there is often a gap between what people say and what they do" (p. 189).

People are often unable to describe in detail even the most mundane of practices that they use and rely upon. In normal circumstances, these practices are tacit, taken-for-granted, seen-but-unnoticed, and are rarely discussed or even thought about (Greatbatch et al., 2001, p. 189).

Finally, the ways that patients have been involved in these studies are mostly limited to what INVOLVE would describe as "participation" (INVOLVE, 2012). Greater patient involvement in the research process may lead to more useful and relevant recommendations.

Participatory research studies investigating or implementing service change

A small number of published studies have outlined IPC research that has engaged patients in participatory research or in researcher roles (Ahmad et al., 2016; Hughes, Blackman, McDonald, Hull, & Fitzpatrick, 2011; Webber, Macpherson, Meagher, Hutchinson, & Lewis,

2012)¹⁶. Two of these studies engaged service users at the organisational level. Hughes *et al.* (2011), educated mental health service users about their organisations' IPC agendas and involved them as IPC auditors. Service user representatives also attended hospital IPC committee meetings. The authors concluded that these contributions were invaluable for effecting ward practice change and also reported improved staff hand hygiene compliance and environmental scores.

Webber *et al.* (2012) sought to involve inpatients at a Canadian rehabilitation centre in an 'action-based' study. Interviews and focus groups were conducted with patients to ascertain their source-isolation experiences and for them to share ideas for improving isolation practices. Through this, staff were able to better understand patients' experiences of source-isolation and to develop successful action plans for ameliorating any negative effects. Patients were invited to participate in the implementation and reporting of all of the action plans, but for reasons beyond the researchers' control, patients participated in the design and implementation of only one.

A third study conducted a five-hour focus group with recent patients and their carers to understand how they define their role in IPC safety. The study also engaged patient representatives as part of the multidisciplinary research team that "took observation notes and analysed the data" collected during the focus groups (Ahmad *et al.*, 2016, p. 322). The main benefit stated for involving a patient representative was to provide inter-rater reliability of the qualitative analysis.

These studies offered patients greater decision-making in research processes and enabled dialogue and the formation of relationships between researchers, clinicians and patients, so as

¹⁶ My literature searches did not cover grey literature and therefore I am likely to have missed relevant but unpublished initiatives undertaken by healthcare providers to involve lay people at facility level.

to identify and act on concerns that matter to service users. However, I would also argue that when lay people are inducted into traditional researcher roles and employ established research methods, such as survey, focus groups and audits, research continues to be conducted at a distance from the complexity of *in situ* activity.

Patient participation in interventions to reduce HAI

Engaging patients to remind healthcare workers to clean their hands

A growing number of studies now involve patients at the frontline of care in interventions aiming to reduce HAIs (see appendix B). The majority of these interventions are designed to educate and empower patients to remind staff to perform hand hygiene before patient contact¹⁷ (Davis, Parand, Pinto, & Buetow, 2015). The outcomes/success of these studies were mainly evaluated by measuring patients' willingness to speak up pre-intervention against post-survey self-reports of actual patient behaviour (Fitzpatrick, Pantle, McLaws, & Hughes, 2009; McGuckin, Taylor, Martin, Porten, & Salcido, 2004; McGuckin et al., 2001; National Patient Safety Agency, 2004; Schwappach, Frank, Buschmann, & Babst, 2013; Schwappach, Frank, Koppenberg, Müller, & Wasserfallen, 2011; Seale, Chughtai, et al., 2015). Another measure was through changes in healthcare workers hand hygiene behaviours, either by direct audit or by measuring hand product usage (Ahmed Awaji & Al-Surimi, 2016; Bischoff, Reynolds, Sessler, Edmond, & Wenzel, 2000; McGuckin et al., 2004; McGuckin et al., 2001; National Patient Safety Agency, 2004; Petersen, Herman, Sturm, Crossno, & Friedman, 2007).

¹⁷ McGuckin and colleagues in the United States (1999) were the first to develop and trial this method which aimed to make healthcare workers more aware of their (sub-optimal) hand hygiene practices. The research team conducted a study in which patients were educated about the importance of staff hand hygiene and were asked to become "Partners In Your Care" by reminding staff to wash their hands. As a result of this intervention, the authors reported that 57% of patients asked a staff member if they had washed their hands and there was a 34% average increase in soap usage. Since then the WHO has adopted this model as part of its multimodal hand hygiene strategy (World Health Organization [WHO], 2009) and many countries have developed their own campaigns (Magiorakos et al., 2009; National Patient Safety Agency, 2004; World Health Organization [WHO], 2012a).

Several of these studies reported increased soap usage, improved hand hygiene compliance of healthcare workers, or that significant numbers of patients, post discharge, stated they had asked their healthcare workers to perform hand hygiene (Ahmed Awaji & Al-Surimi, 2016; Cheng et al., in press; McGuckin et al., 2004; McGuckin et al., 1999; McGuckin et al., 2001). Despite using similar methods, other studies did not find significant changes in patient behaviour (Bischoff et al., 2000; Fitzpatrick et al., 2009; Schwappach et al., 2013; Schwappach et al., 2011; Seale, Chughtai, et al., 2015) or in healthcare provider compliance (Stewardson et al., 2016).

In all, these studies show promise for involving patients in IPC research and interventions. However, their units of measurement tell us little about why strategies that worked in some studies, failed in others. Neither do they shed much light on what needs to be done to improve or sustain such interventions. Accounting for success (or failure) through abstracted measures like soap usage and hand hygiene compliance does not adequately account for the practical and relational tensions that are inherent when asking patients' and healthcare workers to negotiate new and unfamiliar roles. These tensions were acknowledged in pre- and post-survey questions, where patients and staff were asked about 'comfort' or 'positive/negative responses' to interventions, and in the figures describing how many patients did not question their clinicians, but this is where exploration of these matters generally stops. Furthermore, as noted above, self-reported behaviour tools can be unreliable indicators of actual behaviour (Bradburn et al., 1987; Jenner, Fletcher, & Watson, 2006). In the only study that observed *in situ* interactions between staff and patients, 12 (out of 20) patients, who stated they were willing to verbally mention hand hygiene to a healthcare worker, did not do so (Lent et al., 2009).

What is generally concluded from these studies is that personal encouragement and support from healthcare providers is vital to patient involvement (Davis et al., 2015). However, considering the limited literature examining, in depth, patient and/or healthcare worker experiences and concerns, the practicability and acceptability of these kinds of initiatives for those who are expected to enact them, is largely unknown (Butenko, Lockwood, & McArthur, 2015; Davis, Sevdalis, Jacklin, & Vincent, 2012). We know that, in principle many healthcare workers support patient involvement (Davis et al., 2015), but the persistent reluctance of patients to question clinicians suggests this does not translate directly into everyday practice. Clearly a “more collaborative approach that encourages patients and healthcare workers to work together” to achieve a common goal is required (Hrisos & Thomson, 2013, p. 1).

Interventions to improve patients’ hand hygiene

Finally, interventions have also been implemented to improve *patient hand hygiene behaviours*. Many of these studies used a multimodal approach similar to those used to improve clinician hand hygiene compliance - including hand hygiene products at the bedside, patient and staff education and reminders, as well as audit and feedback (Srigley, Furness, & Gardam, 2016). These studies also show potential for reducing HAI. It has been suggested that involving patients in improving their own hand hygiene, rather than encouraging hand hygiene of healthcare workers, not only mitigates the discomfort many patients experience when questioning clinicians, but also engages patients more as true partners in safety (Landers, Abusalem, Coty, & Bingham, 2012). Furthermore, when clinicians are involved in assisting patients with hand hygiene it can inspire the former to improve their own hand hygiene practices (Srigley et al., 2016). I would argue, however, that although the empirical studies appear to be successful and acceptable to all participants, their outcome measures still rely on abstracted data such as audit, self-reported behaviours and acquisition of pathogens,

which again tell us little about *why* they are successful. What I find compelling about these studies is that their interventions require patients and staff to talk to each other about IPC on a regular basis.

2.9 Conclusion

This chapter demonstrated that patients' involvement in IPC remains limited, largely reliant on collecting their views or experiences. While a growing number of studies have involved patients in interventionist research, they typically employed researcher-designed initiatives that defined how patients should enact IPC and examined behaviour based on self-report and other abstract data rather than engaging with the complexity of *in situ* practices. Given the complexity of the relationships/interactions between clinicians and patients on the one hand, and the complexity of everyday care circumstances on the other hand, there is a clear need for research that grapples more closely with these myriad complexities.

It is worth noting here that experience-based co-design (EBCD) is a practice improvement approach that seeks to engage with the complexities that frontline actors face. Using videoed or transcribed stories about experiences of care as a prompt, EBCD fosters face-to-face dialogue between patients, families and clinicians so that together they can co-design solutions to problems (Bate & Robert, 2007a; Donetto, Pierri, Tsianakas, & Robert, 2015). Research that has used EBCD reports positive impacts on staff, patients and the wider organisation (Donetto, Tsianakas, & Robert, 2014). However, EBCD is still constrained by a reliance on participants' *memories* of how they experienced care as the basis for service redesign.

There is therefore, a lack of research that realises patient involvement by enacting it *and* examining it *in situ*, amidst the relational and practical complexities faced by healthcare providers and patients everyday and moment-to-moment. Here, the objectives of health care

and healthcare research “merge in mutually constitutive practices” (Wadmann & Hoeyer, 2014, p. 3). Hor *et al.* (2013) present evidence that by engaging clinicians and patients in this way, “safety [becomes] an ongoing achievement not only of healthcare staff but also of patients, and particularly of patients in interaction with healthcare staff” (p.568).

VRE is a methodology that could be used to explore, with patients, how their everyday interactions with clinicians act as sites of safe (or unsafe) IPC production. The next chapter provides an overview of VRE methodology, including its philosophical and theoretical underpinnings. I then detail how I extended the application of VRE by involving patients in scrutinising *in situ* practice for infection risks.

Chapter Three Methodology and Methods

3.1 Introduction

In the previous chapter, I reviewed the literature on patient involvement in healthcare research and argued for the use of methodologies that award greater primacy to patient expertise and agency in HAI research, particularly research that examines the complexity of clinician-patient relationships and of clinical care delivery *in situ*. In this chapter, I explain how I sought to achieve this by exploring new ways of enacting the methodology – video-reflexive ethnography (VRE) – that was central to the National Health and Medical Research Council (NHMRC) project that funded my PhD research.

I begin in section 3.2 by making explicit the personal and professional experiences that led to my ‘becoming’ a VRE researcher. I do this, not as a ‘self-indulgent catharsis’ (Carter, 2010, p. 147). Rather, drawing on the Deleuzian notion of ‘becoming’ (Lather, 2013), this semi-biographical account aims to show how I developed my research project while, at the same time, learning about and embracing a methodology that is constantly advancing and in development. Through a growing understanding that research need not be conceptualised in fixed or immobile terms, I was able to find new ways to deploy VRE. Through this reflexive activity, I also hope to provide an in-depth “first fieldwork” (Marcus, 2009, p. 7-9) account that can contribute to the advancement of VRE methodology.

Following this semi-biographical account, in section 3.3, I describe the VRE methodology as it has been employed to date, and its philosophical and theoretical underpinnings. I discuss how patients have been involved in VRE research and suggest different ways that VRE might be used to engage patients in infection prevention and control (IPC) research. Section 3.4 concludes the chapter by presenting my exploration of these ideas through my research design and approach.

3.2 ‘Becoming’ a VRE Researcher

My research was first inspired by the works of a group of healthcare researchers, led by Professor Rick Iedema, in Sydney, Australia¹⁸. More recently, the field of VRE research has expanded internationally, to the Netherlands (Mesman, 2016), Scotland (Gordon, Rees, Ker, & Cleland, 2016), and the United States (Carroll, Mesman, & McLeod, 2016; McLeod, Carroll, McAlpine, & Montori, 2016). Over the past decade, these researchers have engaged with clinicians and patients at the frontline of patient care to address quality and safety issues and to effect healthcare improvements. They have also drawn on a range of philosophies and theories in their application of VRE as a unique, innovative and interventionist methodological approach to healthcare improvement (Iedema, Mesman, et al., 2013). The theoretical and methodological underpinnings of VRE therefore are constantly evolving as individual researchers and project teams use the methodology to challenge and explore new territory.

Inspired by these researchers, I sought the following: to experiment with and extend the VRE methodology; to learn alongside patients and healthcare professionals about the hospital system that I work in; to contribute to improved infection control practices; to imagine new ways for patients to become more actively involved in the safety of their care and healthcare research; and, to learn something about myself.

The Researcher

Elizabeth St Pierre points out that we come to a research project long before its official beginning:

¹⁸ Originally at the Centre for Health Communication (CHC), at the University of Technology, Sydney.

You're living the study, you've been talking with people about this thing you've been interested in for some time, you've been reading about it, finding it in novels and movies (St. Pierre, in Guttorm, Hohti, & Paakkari, 2015, p. 18).

And so it was with my research. I didn't 'start' a PhD in March 2012 – this thesis has always been “in the middle”, and connected to many other reference points “from which it grows and which it overflows” (Deleuze & Guattari, 1987, p. 21).

Most of us have been aware of ‘germs’ our whole lives: early memories of our parents teaching us to wash our hands before we eat, or after we go to the toilet; taunts in the playground, ‘boy germs, girl germs, pass it on’; and crossing your fingers to keep you safe. My relationship with bacteria intensified in my teenage years when a rash of pustules planted themselves on my back and refused to leave. One dermatologist prescribed particularly a gruelling twice daily regime - soaking for 10 minutes in a bath of Condys crystals (Potassium permanganate) and then standing to drip dry for 10 minutes, then repeating this twice more, soaking, standing, soaking, standing. Shivering in the cold tiled bathroom in winter, with purple rivers running down my body, I cursed the bacteria that made it so hard to wear a backless dress or a swimming costume. Back then, I didn't really understand that everyday backyard-variety germs could kill. Tetracycline had always been effectively administered for my bouts of childhood tonsillitis to ‘kill the germs’ (so many times that my baby teeth were stained black). As long as we took the medicine, there was nothing to fear. Even through my three childhood operations (adenoids age 7; appendix age 14; tonsils age 16), I don't remember fearing infection.

When I finished school at the end of 1981, I decided to become a nurse. During my hospital training, I developed a deeper understanding of the transmission of pathogens. In nursing school, we experimented with wrapping our hands in toilet paper, touching plates that grew

Escherichia coli (*E. coli*), discarding the toilet paper and touching a clean petri dish. I was amazed to see how much *E. coli* made it through the toilet paper, onto our hands and onto that petri dish, but I still didn't really connect that to the problem of patients acquiring infections in hospital. I was more worried about protecting myself because in the early days of my nursing training gloves were not provided. We washed bodies and cleaned spills with our bare hands and just had to wash them well afterwards.

One day, I walked into a ward and saw two single rooms at the end of the corridor had been cordoned off by rope. Behind the rope, a nurse wearing a white gown, gloves and a facemask, stuffed used linen into a laundry skip. It looked like a scene from a movie, eerie and out of place and I felt a bit scared. That was when I first learned of methicillin-resistant *Staphylococcus aureus* (MRSA) and started to understand the concept of healthcare-associated infection (HAI). These isolation rooms became increasingly common as more and more patients acquired MRSA in our hospital. Usually one or two nurses were specifically assigned to only look after these patients for the shift. Sometimes I was one of those nurses. Patients were often quite sick with MRSA infections, and yet, I don't remember having received much education on how to prevent HAI at this time.

In 1984, to accommodate life as a new single mum, I mostly on a casual basis so I could choose my shifts around day care and school. As a casual nurse, I was rarely invited to staff training or in-services – so perhaps I missed out on being oriented to the infection prevention and control campaigns that were increasingly being implemented in NSW hospitals. Even when I became the clinical nurse educator on a neuroscience ward in a large Sydney hospital in 2005, I do not recall hearing about the *Clean Hands Save Lives* campaign launched by the Clinical Excellence Commission and NSW Department of Health in early 2006 (Pantle, Fitzpatrick, McLaws, & Hughes, 2009).

In 2007, I took a position as a graduate nurse coordinator at a Johns Hopkins-managed hospital in the Middle East. In this role, I experienced a huge learning curve around infection prevention and control. For the first time in my life, as part of my visa entry requirements, I was screened for MRSA. The North American hospital system had already adopted a hand hygiene campaign based on the Geneva Hand Hygiene Model (Pittet et al., 2000) and it was rather a shock for me to find myself in a hospital that had very few soap and water hand-washing facilities, but an abundance of alcohol-based hand rub stations. For the first time, I was hyper aware of hand hygiene as a discipline, guided by a set of rules (the 5 moments of hand hygiene (WHO, 2009) (see appendix A); and, with running water not always available, I had to quickly get used to hand rubs. I also experienced what it was like to be the subject of hand hygiene audits. Middle management and ward meetings always included a report from the infection control department and I included an infection control component in each of the study days I held with the new graduates.

Eventually, I shared an office with an infection control nurse and her passion for her job inspired me to think about further studies in infection control. So, in late 2011, when circumstances meant that I had to leave the Middle East and return to Australia, I found myself typing “Infection Control” and “PhD” into the Google search engine. The top hit was an advertised PhD scholarship located with the Centre for Health Communication (CHC) at the University of Technology, Sydney, which was part of an NHMRC-funded project seeking to reduce MRSA transmission in hospitals. I applied via email and three weeks later, back in Australia, I attended an interview, secured the scholarship and posted on Facebook – “I am now officially a PhD student.”

The last 5 years of doing my PhD research have opened up a whole new way for me to look at the world and especially at my hospital work. When I was a nurse educator, I trained

people in tasks and procedures and then I assessed their competence. If they didn't pass, I educated them a bit more. In the Middle East, we educators would construct vast numbers of detailed, tick-a-box, competencies and we assessed peoples' performances of these in a large hall filled with mock procedure stations. In hindsight, I think it was a waste of time. What we asked of these nurses was totally impractical to perform in their everyday work and, when they returned to the wards, they did not. But the competencies were duly filed away for the next hospital accreditation and upper management was happy. At the CHC, research was focused instead on how these tasks and procedures play out at the frontline, and on what can be accomplished amidst the complexities of everyday healthcare. I was surrounded by researchers who talked about theories that I had never heard of, and used research methods I was totally unfamiliar with. They were incredibly welcoming, however, and soon my whole way of thinking about healthcare work and education was turned on its head.

Seeing things differently

The NHMRC project that funded my PhD was entitled 'Strengthening frontline clinicians' infection control: A multi-method study to reduce MRSA infection and transmission'¹⁹. This project was designed with the aim of changing clinicians' beliefs and practices about infection control in order to lower HAI rates using a multi-method design. The quantitative arm of the design was familiar to me: a pre/post survey that would detect clinicians changing attentiveness to infection risk through regular reporting to them of 1) hand hygiene audit data and 2) MRSA transmission data, using a new highly sensitive, rapid and routine strain-typing method. This fitted well with my positivist, knowledge-based nurse training; if people know the rules and the consequences of not following the rules then they will change their practice.

¹⁹ This was supported by an NHMRC project grant (#1009178)

My research, however, was to be part of the qualitative arm of the project which employed VRE: videoing everyday practice and then reflecting on this footage with clinicians to explore sources of and solutions to infection risks. This was definitely not as familiar to me, but my one directive was that I should somehow use VRE to contribute to the project.

On the one hand, I was fortunate to be in the position of entering a ready field site, with an agreed-upon methodology, and to be researching alongside a senior researcher who was also my PhD co-supervisor. On the other hand, I was not setting out on a familiar, traditional research course where I would start with a research problem/question and then make decisions about “what strategy seems likely to provide what [I am] looking for” (Crotty, 1998, p. 13). My methodology was pre-given and before I could do anything else I needed to find out just what VRE was.

In the early days of my PhD, I was able to approach several colleagues at the CHC who had been using VRE in various projects. I read publications on VRE written by CHC members (e.g. Carroll, 2009a; Carroll, 2009b; Carroll et al., 2008; Iedema, 2011a; Iedema & Carroll, 2011), participated in CHC reading groups, and attended NHMRC project meetings where VRE was discussed. It became quite clear that VRE would offer few instructions *a priori* for how I should carry out research. Rather, I was given advice like “engage in the mess”, “experiment with the methodology”, and “do something new”. I learnt that I would not be a detached observer, collecting video data and taking it away to analyse it at my researcher desk. I would need to understand the theory behind VRE because *this* would guide my research actions (Jackson & Mazzei, 2012).

The larger NHMRC study was to be conducted in three sites across two hospitals. Dr Su-yin Hor, the senior researcher on the project, commenced fieldwork at the first site in July 2012, four months into my PhD. I visited this site with her while I was working out the focus of my

PhD research, which would commence at the second site. It was largely through observing, assisting and debriefing with her that I began to understand the philosophical perspectives underpinning VRE in practice.

Later, in August 2013, six months after I began my own fieldwork, Iedema, Mesman and Carroll (2013) published a book that brought together and explained, in detail, the theoretical foundations of VRE. After several readings of the book, I started to get a firmer grip on how and why my use of VRE had thus far been successful in engaging with the patients and clinicians I was researching with.

In early 2014, a group of VRE researchers (including myself) organised and delivered a three-day course that presented the practical, technical, ethical and theoretical dimensions of using VRE in healthcare settings. This course cemented my understandings of different models that researchers have developed over the years for using VRE²⁰. For example: 1) the early ‘clinalyst’ model (Iedema & Carroll, 2011), where the researcher functions as an ‘outsider’ analyst/catalyst, who assists the researched (insiders) to reflect on and revise their practices by watching footage of everyday work; 2) the ‘assistant’ model, where the researcher’s role is to prepare clinicians to become clinalysts themselves with the researcher eventually becoming obsolete (Iedema, Merrick, Kerridge, et al., 2009; Mesman, 2016); 3) the ‘advocate model’, which calls for the researcher to become implicated in, and affected by, the research, harnessing affect as a driver for motivating reflexivity and change (Iedema & Carroll, 2015); and 4) models that seek involve patients more actively in VRE (Collier, 2013).

In the following sections, I describe my understandings and particular interpretations of VRE as they informed my research. I acknowledge, however, that because VRE is continually developing, aligning with different but compatible theories, and can also be used in

²⁰ Katherine Carroll’s presentation at this symposium spoke directly about these models (Carroll, 2014).

combination with other methods, that others may have approached this VRE research differently.

3.3 Video-Reflexive Ethnography

Philosophical and theoretical underpinnings

Video-reflexive ethnography is a methodology that uses video footage of everyday practices as a resource by which to intervene in existing relationships and practices to effect learning and change (Iedema, Mesman, et al., 2013). It is a reflexive, collaborative and interventionist methodology that does not seek to represent what people do and say as a comprehensive or final knowledge. Rather, its focus is directed at the ongoing learning of participants, rather than the knowledge gained by the researcher. This is because VRE is oriented by the assumptions that healthcare work is complex; that information about this work will always be incomplete; and that it is therefore necessary for practitioners to be assisted to collectively and reflexively develop their own knowledge, skills and solutions to meet the rapidly changing situations and problems that they find themselves confronted with (Iedema, Mesman, et al., 2013). VRE researchers seek to engender this reflexive capability by videoing real-time practices and showing the footage back to participants so that they can collectively make sense of their work and workplace contexts. This speaks to an unconventional ontology – one that focuses on the complexities of *in situ* activity rather than what people say they do (Iedema, Mesman, et al., 2013). It also speaks to an unconventional epistemology by suggesting that “knowledge arises from what different people can tell each other, and it can change depending on who is present and how they share it with each other” (Iedema, Mesman, et al., 2013, p. 73). Central to VRE therefore is an acknowledgement of the expertise of frontline actors and of the need to collaborate *with* them to find ways to improve healthcare.

VRE methodology is therefore framed in contrast to the principles underpinning contemporary perceptions of patient safety, including infection prevention and control. Predominant 'top-down' approaches, such as the programs I carried out in my previous educator roles, aim to ensure that clinicians 'know what to do', based on best available evidence developed by 'experts', and to amend any resistance or avoidance through (often quantitative) feedback and further education (Iedema, 2011c; King et al., 2008). This privileging of individuals' general knowledge and personal motivation, however, ignores the complex and unpredictable circumstances in which clinicians and patients find themselves, and which are central to whether and how (well) practitioners enact patient safety (Iedema, Mesman, et al., 2013). Increasingly, researchers and policy makers are recognising that relying on 'rule compliance'-type approaches to patient safety can hinder the optimisation of care safety and quality (Allard & Bleakley, 2016; Bevan & Fairman, 2014; Dekker, 2011; Olsen et al., 2007; Vincent & Amalberti, 2016). They call for fresh approaches to patient safety issues that reduce reliance on expertise-centred approaches and recognise the significance of frontline actors' own insights, experiences and commitment to achieving changes needed for improving safety. Many of these commentators, however, fall short of articulating a clear pedagogy for how this can be achieved.

VRE offers one such pedagogy for assisting frontline actors to 'gain traction with' (Carroll, 2009b), and manage, everyday healthcare complexities. This pedagogy is anchored in a learning theory that is very different to the knowledge *acquisition* model outlined above. VRE draws on the work of learning theorists such as Biesta (2005) and Dewey (1922), as well as affect theorists like Fox (2015) to capitalise on the learning that occurs as a *response* to being confronted with taken-for-granted ways of being. People who engage in reflexive analysis of their everyday practices become more aware of the complex and habituated nature

of these practices, and this can result in an emotional response that is the impetus for learning and change.

Impulses (affects, emotions) are the pivots upon which the reorganization of activities turn, they are the agencies of deviation, for giving new directions to old habits and changing their quality. (Dewey, 1922, p. 67)

From this viewpoint, learning is contingent on being affected and it follows that “the greater our power to be affected, the greater our power to act” (Hardt, 2007, p. x) – or, to affect, in turn (Fox 2015). By becoming more aware of, and affected by, the strengths and opportunities for change that are inherent in their shared practices and relationships, participants can be motivated to reinforce or adapt them accordingly. Underlying this is the principle of ‘exnovation’ (de Wilde, 2000; Iedema, Mesman, et al., 2013; Mesman, 2011), which is:

The attempt to foreground what is already present - though hidden - in specific practices, to render explicit what is implicit in them [...] exnovation does justice to the creativity and experience of the participants, in their effort to assert themselves in the particular dynamic of the practice they are involved in.
(Mesman, 2011, p. 72)

Exnovation is about uncovering what *works well* as much as what can be done differently. Thus, one of the aims of VRE is to assist clinicians to scrutinise their own everyday practices so that they gain awareness of their *existing* safety competences as well as increasing their agency and control over what needs to change.

Furthermore, VRE values learning as a *social* activity:

For practitioners to address and intervene in the habituated dimensions of what they do and resolve those dissonances, they need to develop ways of subjecting their collective competence to reflexive deliberation. (Iedema, Mesman, et al., 2013, p. 55)

Put differently, in contemporary, fast-paced healthcare environments it is no longer feasible that one individual alone can accumulate, retain or rely on an ever-expanding and contested body of knowledge to deal with the challenges that arise. Knowledge sharing is only one step towards a ‘collective competence’ (Boreham, 2004) that enables clinicians to do complex work effectively and safely. Collaborative and reflexive deliberation in VRE, however, opens up spaces for people to affect and be affected by each other, as they negotiate different viewpoints, and position themselves in relation to visual evidence of their practices and relationships (Carroll, 2009a). This process enhances their “ability to intervene in their own and each other’s competences,” thereby developing a “distributed intelligence” (Iedema, Mesman, et al., 2013, p. 56).

Thus, VRE theorists hold that “learning arises from the interruption of taken-as-given practices and behaviours because it engenders [collaborative] reflexivity” (Iedema, Mesman, et al., 2013, p. 189). Video is critical to engendering this reflexivity on several levels. The moving image can reproduce the dynamics of everyday practice, revealing the complexity of these practices and rendering them tangible and discussable. Unlike methods such as survey and interview that rely on participants’ memories and espoused views of how care happens, video footage allows participants to refer, together, to specific aspects of care practices and social interactions videoed in real-time. What participants often see in the footage are the

messy details and habituations that participants have ‘learned to forget’ in the day-to-day business of their work and lives (Iedema, Mesman, et al., 2013; Wears & Schubert, 2016).

In addition, video footage used this way also has a *hologrammatic* effect, extending beyond the events shown in the footage, whereby for participants:

Witnessing their activities on-screen can act as a springboard for seeing through and across the organisation of work, into the past, into the future and out into the present organisation of field practices (Iedema, Mesman, et al., 2013, p. 180).

In other words, people who were featured in the footage, or who were otherwise close to the videoed events, bring to the viewing their understanding of the events that led up to the those shown on the screen; they can remember what happened next, and can link what they see in the footage to other aspects of their work and work contexts. Furthermore, by providing a multi-modal record of an event that details sounds, expressions, gestures and so forth (Jewitt, 2012), video can also connect people to tacit meanings and feelings embedded in their work practices and how these can impact on behaviours and relationships (Carroll, 2009a; Pink, 2007). In this way video can assist participants to come to terms with both the technical *and* the affective or relational dimensions of health care.

In his book *Parables for the Virtual*, Massumi (2002) explains how watching the moving image transforms people by enabling the *seeing of oneself as others see us*. In the moving image, we are confronted with a very different view from the private mental image that we form about ourselves. Our understanding of how we act and how we relate to others is displaced (p. 46-67). The disconnect between these two views can provide the impulse for learning and the motivation to create new and common futures. The kind of learning we hope

to achieve by using VRE therefore requires participants to become vulnerable; it asks everyone involved to put at risk “not just specific aspects of their behaviour [...] but their personal identity and, thereby, their social and organisational relationships” (Iedema, 2011a, pp. i84-i85). The reflexive skills and careful facilitation of the researcher are therefore crucial to using VRE successfully. To establish safe and productive learning environments, facilitators must be constantly sensitive and adaptive to the changing contexts and politics of the work environment during videoing, editing and the group reflexive sessions (Carroll, 2009a), including reflexively (and in partnership with those featured in footage) deciding what footage should be shown back in reflexive sessions and in assessing and responding to participants’ reactions and dynamics (Collier & Wyer, 2016).

These last points highlight that not only does VRE call for a different way of learning, it is also a different way of researching. Rather than taking the predominant research stance of the distanced, objective observer, in VRE the researcher must become embroiled in *in situ* activities, relationships and tensions, engaging with participants to co-produce knowledge and facilitating research relationships that can assist everyone to confront change. VRE does not offer a prescriptive methodological recipe for how to conduct research; however, most VRE research includes ethnographic methods such as interviews and observations, which are used, especially, at the beginning, to familiarise the researcher with the field and to develop relationships of trust with participants. When participants are comfortable, negotiations then take place about what will be videoed, and who will do the videoing. As mentioned above, the researcher then confers with those videoed to decide what will be shown back in reflexive sessions. Reflexive sessions may also culminate in reflexive ‘feedback’ sessions, which sum up the main issues raised and solutions developed, presented so that participants can make firmer plans of action. At each stage, there is a blurring of lines between researcher and participants as they engage in a collaborative process of intertwined data creation and

analysis that “feed into each other not only iteratively but also rapidly” (Hor, Carroll, Collier, Lenne, & Wyer, 2016, p. 24). Analysis occurs “everywhere and all the time” (St. Pierre & Jackson, 2014, p. 717) as we create data with participants. Through this, we become sensitised to what matters sufficiently to warrant action (Iedema & Carroll, 2015), a process which in turn informs new directions for the research. This points to the significant ‘thinking with theory’ (Jackson & Mazzei, 2013) that researchers must engage in at every step of VRE research, to develop relationships and safe spaces that enable people to confront complexity, to affect and be affected enough to want to learn and become ‘more’ (Hor et al., 2016; Iedema, Mesman, et al., 2013).

Using video-reflexive ethnography with patients

Over the last decade, VRE has been used in a variety of healthcare settings and to address a diverse range of patient care issues. For example: ward round practices (Carroll et al., 2008) and safe communication (Hor et al., 2014) in intensive care units; handover in emergency departments (Carroll & Mesman, 2011; Iedema, Ball, et al., 2012); ‘brilliant’ organisational experiences in palliative care services (Dadich, Hodgins, & Collier, 2016, July); effective communication between medical staff and laboratory scientists (Carroll et al., 2016; Forsyth, 2009); and infection control practices in neonatal intensive care (Mesman, 2016) and adult acute care (Iedema et al., 2015).

Until recently, most VRE research in healthcare has focused on exnovation work with clinicians. Two notable exceptions are: an end-of-life care study where patients viewed footage of their own narratives of care, gaining new insights into their own expertise around patient safety (Collier, Sorensen, & Iedema, 2016); and a primary health care study in which patients viewed footage to explore the concept of respect in clinical encounters (McLeod et

al., 2016).²¹ When I started my PhD, the former study was nearing completion, and the latter had not yet been conceived.

In Chapter 1, I briefly explained some of my reasons for inviting patients to be the central focus of my research, and in Chapter 2, I laid out some of the motivations and debates that surround the move toward greater patient involvement in their own care and in patient safety research. To sum up, I wanted patients to be actively involved in this research not just for ethical reasons based on their autonomous right to be involved (INVOLVE, 2012; Ives et al., 2013; Shippee et al., 2015), or their moral obligation to be involved (Faden et al., 2013), but also because patients have existing expertise and insights that are critical for improving patient safety (Collier, Sorensen, & Iedema, 2016; Hor et al., 2013).

I was inspired by Aileen Collier's end-of-life care study (Collier et al., 2016), which was the first to extend the use of VRE to actively involve patients. In this study, patients were provided opportunities to video narrative accounts of their care and then review that footage with the researcher to decide what would be fed back to the clinicians that cared for them. As far as I was aware, however, there had been no video studies in which patients had been involved in scrutinizing footage of their own *clinical care interactions* to identify patient safety risks. I decided that the main focus of my research would be to undertake VRE with patients and carers by asking them to analyse footage of their own clinical care for infection transmission risks. I saw this as a chance to co-research with patients, in line with the values of the patient involvement literature outlined in Chapter 2, and in ways that would acknowledge and respect patients' expertise and contributions to patient safety. I also wondered if undertaking this kind of exnovation work with patients could engender in them a

²¹ At the time of writing, Danielle Bywaters is also using VRE with patients in her PhD study at the University of Tasmania. Danielle videos nurse/patient education sessions and shows this footage back to patients and to the nurses.

more critical attitude to IPC and enhance their sense of agency as it has for clinicians involved in VRE.

3.4 This study

The first thing I want them to do is read, read, read and then “do” the next thing that makes sense and to keep doing the next things and then all that doing is a methodology (St. Pierre, in Guttorm et al., 2015, p. 16).

At the beginning of this chapter, I gave an in-depth background to how I came to VRE research and the background to the NHMRC project that funded my PhD study. I will now explain how this background, along with the methodological philosophy and approach I have set out above, shaped my research project in practical terms. In many ways I was enacting the advice that St. Pierre gives above. Informed by my continued readings, my discussions with colleagues and my developing understanding of the theoretical underpinnings of VRE, I just kept doing the next thing that made sense, and in doing so realised new ways of enacting VRE.

Research aims and research questions

At the beginning, I had two broad aims for my research. The first was to invite patients to become more active participants in HAI research so that together we could examine, *in situ*, if and how they negotiate and enact IPC safeties. My second aim was to use VRE in new ways. I planned to video episodes of care, show this footage back to patients and engage in reflexive discussions with them about real-time care practices. I wanted to explore if this might have any transformative impacts on them.

With these two aims in mind, my early research questions were:

1. How do patients understand, negotiate and enact safe or unsafe IPC practices?

2. Can VRE support patients to better understand IPC practices, and how their IPC needs might be better met?

Initially, this was as far as I planned to use VRE. However, I soon also saw a natural opportunity to extend VRE by feeding back the patients' commentaries on care to the clinicians who cared for them. I wondered if, being confronted with footage of clinical care, in conjunction with footage of patients discussing the same interactions, might assist clinicians to see IPC from a different perspective (the patients' perspective); and if this could broaden their capacity and appreciation for patients' expertise and involvement in IPC. I had not come across such a shrinking of the patient/clinician feedback loop in the patient safety literature I had read, and believed that it would offer rich feedback grounded in context that could provide powerful motivation for more dialogue with patients about IPC. I developed a third research question:

3. Can VRE strengthen clinicians' awareness of and commitment to patient/clinician relationships that support patient involvement in IPC?

In Table 3.1, we can see a basic outline of: how VRE research has been used with clinicians in patient safety research; how Collier (2013) extended VRE to include patients' and families' narrative accounts of care (Study 1); and the plan I made to extend VRE further still, by including footage of care alongside patients' commentary on that care in my feedback to clinicians (Study 2). This table is reproduced from a published paper found in Chapter 4 (Collier & Wyer, 2016).

Table 3.1: Extending VRE to use with Patients

Basic Plan for VRE With Clinicians ^a	Study 1—End of Life	Study 2—Infection Control
Phase 1		
Ethnographic field observations and field notes	Ethnographic field observations and field notes (EFN)	Ethnographic field observations and field notes (EFN)
FI/SSI with staff (audio/video-recorded and transcribed)	FI/SSI with staff, patients and families (audio/video-recorded and transcribed)	FI/SSI with staff, patients and families (audio/video-recorded and transcribed)
Analysis	Analysis	Analysis
Issues identified by Clinicians Researcher/s	Issues identified by Patients and families Clinicians Researcher	Issues identified by Patients and families Clinicians Researcher
Phase 2		
Video-ethnography	Video-ethnography	Video-ethnography
Videoing environments and practices identified in Phase 1	Videoing environments and patient/family narratives to gain insight into issues identified in Phase 1	Videoing nurse/patient care interactions around issues identified in Phase 1
Videoing undertaken by researcher and/or clinicians	Researcher, patients, and families collected footage	Researcher usually held camera but the focus was directed by participants
Analysis	VRS with patients and families	VRS with patients
Researchers and clinicians involved in videoing decide which footage will be edited into short clips for feedback and discussion	Each participant was provided with an opportunity to view footage in its entirety and to contribute to decisions about which footage to show back to clinicians in video-reflexive sessions	Each patient viewed their footage, analyzing infection control moments and staff/patient interactions These sessions were video- or audio-recorded
VRS with clinicians		
Reflexive focus groups—clinicians analyze footage for strengths and areas for improvement		Each patient then contributed to decisions about the creation of edited clips/transcribed text for feedback to the nurses
	Phase 3	
	VRS with clinicians and other stakeholders	VRS with nurses
	Patient insights fed back to clinicians in reflexive focus groups for collaborative discussion	Care interaction and accompanying patient analysis fed back to nurses in reflexive focus groups for collaborative discussion

Note. The phases and stages described in this table are iterative and overlapping. Although analysis is shown as a discrete step in this table, analysis continues throughout the entire process of the research. VRE = video-reflexive ethnography; EFN = Ethnographic field notes; FI/SSI = field/semi-structured interview; VRS = video-reflexive session.

^aThis column is not a prescriptive checklist for how VRE is always used with clinicians. Rather, it shows a basic representation of VRE work flow as it has sometimes been used. For examples, see Carroll, Iedema, and Kerridge (2008) and Hor, Iedema, and Manias (2014).

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The field site

My fieldwork was mainly conducted in a 66-bed adult surgical unit, comprising two mixed general wards. The entire unit comprised of two rectangular wings that spread out on an ‘east-west’ axis from a public entry at the centre of one side. The patient rooms were located on the outer perimeter of the rectangle with the workstations and utility rooms generally located in a long strip down the centre of the rectangle. If you turned left when you entered the main entrance the patient room numbers started from bed 1, and followed around the perimeter of the unit to bed 66 which was situated near the right hand side of the entrance. This seamless numbering of the patients rooms, and the lack of dividing wall gave the

appearance of one united ward. However, it was actually two wards, one beginning from bed 1 to 29, the other from bed 30 to 66, each staffed by a different nurse unit manager (NUM) and a distinct nursing team.

Patient transfers between the two wards were frequent; however, each ward generally housed different specialties: vascular and plastic surgery and surgical oncology in ward A, and upper gastrointestinal, colorectal and ear, nose and throat surgery, as well as ophthalmology in ward B²².

I spent roughly equal time on both wards, mostly in patients' rooms, talking to patients.

Patients were accommodated in either single rooms or four-bed rooms. Each single room had its own bathroom/shower facilities located inside the room. Single rooms were most often used to care for patients infected or colonised with MROs or other infectious agents. Signage on the patient's doors indicated the transmission precautions required: contact, droplet and/or airborne precautions. At the entrance to these rooms essential personal protective equipment was provided: gloves, gowns, masks and eye protection. Alcohol based hand rub (ABHR) and detergent wipes for cleaning equipment were also available. Dedicated clinical equipment²³ for patient care was assigned for patients known to be carrying an MRO, but this was not always possible, and it was expected that shared equipment would be cleaned by clinicians between uses. A hand basin with running water and liquid soap was located inside each patient room and ABHR was supposed to be attached to the end each patient's bed.²⁴

²² These were not the actual names of the wards but will be used to describe them in this chapter.

²³ For example: stethoscopes, sphygmomanometers, thermometers etc.

²⁴ It was hospital policy to have bottles of ABHR at the end of each bed and audits were intended to keep track of compliance on each ward. However, beds frequently moved between hospital locations and beds arriving into the unit from other places did not always have a bracket to attach the bottle. Staff also told me that brackets were often knocked off beds when they were in transit.

Four-bed rooms were generally used for patients who were not infectious, and curtains separated the beds in these rooms. A shared toilet and a separate shared shower were located at the entrance to these rooms. One hand basin with running water and liquid soap was also located at the entrance to the room, with boxes of gloves in various sizes placed in brackets above the sink. Again, ABHR was supposed to be found at the end of each patient's bed. There were times during this study that the number of colonised patients exceeded the number of single rooms available. This happened in the first week of the study when an initial point prevalence survey²⁵ revealed that 42% of patients screened were colonised with MRSA (68% in ward A and 23% in ward B).²⁶ On this occasion, a group of four colonised patients were cohorted together in a four-bed room. A trolley stocked with personal protective equipment was positioned at the entrance to the room.

A small shared kitchen for patient and visitor use could be found in each ward. These contained a sink with running water, a refrigerator, an urn, and tea and coffee-making facilities. At the end of each ward was a patient lounge in which a few chairs were placed. This area was also used to store large equipment like patient-hoists, walking frames, and wooden stairs that were used by physiotherapists during rehabilitation sessions. Patients who were colonised or infected with MROs used both of these communal spaces. Each ward had a nurse tearoom that also doubled as an education room for in-service and was used for shift handover. The staff reflexive sessions were held in these rooms.

One dirty utility room was located in each ward. Bedpans and bottles were all cleaned in this room and clinical waste from single or four-bed rooms would often be carried through the

²⁵ A point prevalence survey aims to determine the number of people who have a disease at one particular point in time. In this ward, all patients were to be screened (by swabbing their nose and perineum) to determine if they were carrying MRSA.

²⁶ Although MRSA acquisition and environmental contamination were relatively common on this ward the staff were shocked and surprised by the high prevalence of MRSA identified in the survey.

ward to large bins in the dirty utility room. The ward cleaners also had a small storeroom that housed their cleaning products and equipment.

The main reception desk on each ward was a busy station used by all staff. Both were square shaped. Three sides of the square were formed by a divider that was high enough on the outside for staff to stand and write at. Patients could often be seen leaning on this divider when they came out to make enquiries or to use the ward telephones. Inside of this divider were desks at seat height, set with computers and telephones. A dedicated ward clerk sat at the desk in front of the main computer and took patient or visitor enquiries. Nurses, doctors and allied health staff used the desks for filling out paperwork and writing patients' medical notes. This was also an area that nurses would congregate at less busy times.

The back wall of the station comprised pigeonholes that housed patients' files and stationary. Throughout the day, patients' files were moved from this area and taken on doctors' rounds or nurses' medications rounds and were often taken into patients rooms then returned to their pigeonhole. In all, these stations were major locations where human and material traffic passed between patient areas and back, and MRSA was found at one of these desks several times during environmental contamination surveys.

Sometimes, I travelled with patients to other locations in the hospital. Our experiences at these locations were important for both of us in making sense of IPC. For example, I followed Miller²⁷, who was colonised with MRSA, to the patient rehabilitation gym and was able to observe and discuss with him how the physiotherapists managed MRO-colonised and non-colonised patients in a shared space. Most days, I would walk past the area where patients congregated to smoke, and would see patients who were colonised sitting, and sharing cigarettes and other items, with non-colonised patients.

²⁷ In this thesis I use either the patients' real names or pseudonyms, depending on their preferences.

I maintained contact with several of the patient participants throughout my PhD candidature and also met with them at outpatient clinics and other venues. I attended chemotherapy sessions with Destiny, and podiatry, ophthalmology and day surgery with James. I visited Gary, June and Rob when they were re-admitted as inpatients for complications in other wards. At times I met with Clyde, Destiny, James and Gary to share a coffee in the hospital cafeteria and to discuss their developing views on IPC. Many of these people pointed out the seeming illogic between their isolation as patients colonised with MRSA when they were inpatients compared to the freedoms they experienced as outpatients, despite still being colonised.

There were other departments and people that were important to this study. First were the specialist nurses in the infection prevention and control department. This unit was located on the same level as wards A and B, a few minutes walk away, on the other side of the hospital. These five nurses were always available for me to drop in and ask questions about IPC processes I did not understand. They allowed me to store equipment in their office, use their computers, and invited me to their staff meetings and lunches. Several times I shadowed them on their IPC rounds throughout the hospital as they visited patients newly identified with colonisation or infections, and explained isolation measures to staff. They were an invaluable information resource.

The other important department was the diagnostic microbiology laboratory attached to the hospital. For a short while during my PhD, I was employed casually through this department as a research assistant to investigate transmission sources, routes and vectors of MRSA. This involved reviewing patient and hospital records and, where appropriate, talking to patients and staff about their views on the most likely sequence of events leading to individual patient acquisition of MRSA. I spent a lot of time in offices near the laboratories during this time and

could observe, from a distance, the scientists and technicians working with a broad range of viral, bacterial and fungal pathogens. Although this work was separate to my PhD research, it did enrich my understandings of how infection transmission affects patients and how IPC is managed through the many departments in the hospital. It also informed aspects of my thinking for the academic publications in this thesis and the content of my conference presentations.

The fieldwork schedule

My fieldwork took place between March 2013 and April 2014 – a total of thirteen months. However, as I explained earlier, my association at the hospital encompassed both my PhD fieldwork and a research assistant position. These two engagements overlapped but can be roughly mapped out in two stages. The first stage, which began in March 2013 and finished in November 2013, was spent almost entirely on the surgical unit and generated the bulk of the data that I draw on for my empirical chapters. The second stage began in late November 2013 and finished in April 2014. This was the time I was employed as a research assistant on a related MRSA project. During this work I spent time investigating transmission events that occurred in the wider hospital and this provided opportunities to meet new patients. Insights from the patients I interviewed during this period informed my thinking in the empirical chapters that follow. During this period I also engaged in more video work with patients on the surgical unit but I have not included this activity in my empirical chapters. I will explain my reasons for this later in my conclusion chapter, but briefly, this was because I had started to push the application of VRE further with these reflexive sessions by viewing the footage along with the patient *and* the nurse involved, at the same time. Although this was an interesting and productive exploration of reflexive activity, I do not feel that it was explored in enough depth to be included in this thesis. In my conclusion chapter I make further recommendations for extending VRE in this way.

I attended the hospital on weekdays and weekends, mostly between the hours of 7 a.m. and 7 p.m. to accommodate patients' sleep periods. I also attended one overnight shift with the senior researcher to conduct two reflexive sessions with night duty nurses.

Participants

Ethics approval was granted for the clinician study in 2011 and fieldwork was completed at the first site by the end of 2012. In early 2013, I was still waiting on an ethics amendment to be able to include patients as active participants in VRE at the second site: the surgical unit. While I was waiting, I assisted the senior researcher with conducting information sessions for staff on the surgical unit and I was able to inform them of my provisional plans for patient involvement. My ethics approval was granted on February 8, 2013.

Clinician recruitment – ward nursing staff

For each ward, the senior researcher and I met with the nurse manager and clinical nurse educator to discuss the project and to organise the means to brief the nurses. We acquainted the ward staff with the project through information sessions, handouts (see Appendix C) and emails. I explained the patient project to them but also advised that any work with patients was pending final site-specific ethics approval. The participant information and consent form for clinicians (see Appendix D) was the same for the larger project and the patient project so the senior researcher and I both kept track of the names of clinicians who had signed consent forms. Once my ethics was approved, any consent forms I collected from nurses that I recruited to the study were handed to the senior researcher. Participation was voluntary and the nurses could withdraw from the study at any time.

Ward nurses could be involved in the patient study in two ways. Some were invited to be videoed while attending to patient care, knowing that this footage would be shown back to the patients. None of the nurses who were invited to do this refused. Their written consents

were obtained for this, but consent was also verbally negotiated on a continuing basis: prior to and during videoing, and before any sections of the resulting footage were shown back to other parties, including patients.

Nurses could also be involved by attending patient-feedback reflexive sessions. Written consent was required to attend these sessions, which were also videoed. The nurses could ask for videoing to be paused or ceased at any time. They could also leave the reflexive session at any time.

As explained earlier, there was considerable overlap between clinicians involved in the larger project and my project, which means that some clinicians who participated in my study had initially given their written consent to the larger project. Table 3.2 represents the number of consenting clinicians who participated in the patient project.

Table 3.2: Number of Clinician Participants by Profession

Number of clinicians	Profession/position
2	Infection control practitioners (ICP)
28	Ward nurses (RNs and students)
3	Clinical nurse consultants (CNC)
2	Clinical nurse educators (CNE)
1	Doctor
1	Phlebotomist
37	TOTAL

Patient recruitment

As described above, I met with the nurses in the infection control department (also known as infection control practitioners or ICPs) several times in early 2013 and heard about their

plans for a point prevalence survey in early March. I saw an opportunity to begin recruiting patients to my video research, and obtained permission from the ICPs for the point prevalence survey to be videoed, with the aim of showing the footage back to patients.

On the day prior to the point prevalence survey, I visited every patient in the unit to explain the study and my role as a PhD researcher. I explained that I was committed, as were the staff on the unit, to finding better ways to reduce HAIs, and that central to this was for us to listen to patient and visitor perspectives. I suggested ways that they could become involved in the research, such as an informal conversation or a more formal interview, but I also asked them if there was any other way that they might like to be involved. I made it clear that participation was totally voluntary and to decline would not affect their care. I also discussed with them how we had been using video with the staff to help understand infection risks and explained how I would like to video infection control activities going on in the ward, or any other activity that they (patients) thought pertained to infection risk, and then review that footage with them. I left an information handout (see Appendix C) and a patient/visitor consent form (see Appendix E) with them for consideration. I returned later in the day to gauge their interest in participating and made a note of those who were willing and those who stated they were not at all interested. On the day of the point prevalence survey, I shadowed the ICPs and when we approached a patient who had shown interest the previous day I asked if they would consent to my videoing the nasal swab. If they said yes, I obtained written consent. Twelve patients agreed to be videoed.

Over the following months, I continued to approach patients and visitors at their bedside. Sometimes I would ask the nurses for their opinion about which patients I should approach, but I found that the patients who the nurses claimed would not be interested were sometimes the ones who were most keen to tell their story or offer insights. During these conversations, I

presented them with the patient information sheet (see Appendix C) and offered the avenues for participation as outlined above. If they refused at this time, I would thank them for their time and leave. If they expressed interest, I would provide them with a consent form (see Appendix E) and explain its contents. Sometimes, after going through this 5-page document, filled with academic and medical jargon, patients retracted their interest. Again, I would thank them for their time and leave.

When patients were keen to proceed, most initially preferred being interviewed to videoing care. During the interview process, however, some became more interested in watching footage of care practices. Often, after a patient decided they would like to be involved in video-reflexive activity, I would spend many hours (sometimes over many days) negotiating with the patient and nursing staff and waiting for the ‘right’ time to video, but then something would happen and it was no longer possible to do so: the patient might have been discharged; or the procedure we were going to video might be postponed or cancelled; or the patient felt too tired that day; or the nurse who had consented to videoing was not on duty that shift. I did not view this as a waste of time. Rather, these experiences taught me how to be more responsive and adaptive in my research. For example, I became less timid about asking busy nurses to participate in on-the-spot filming, realising that they did usually feel able to say no if they did not want to. I also made better use of the time I spent waiting to video a pre-arranged care episode, by building relationships with new patients or engaging in more ethnographic fieldwork that might inform future research.

Two patients, June and James, found out about the patient project through the larger clinician study and asked to meet me and be involved in video work. At June’s suggestion, we videoed a complicated dressing that was attended on her leg wound every second day. The other

patient, James, suggested we just set the camera up in his room and video some of the activities that occurred in his isolation room during a morning shift.

The above shows that recruiting patients into a VRE study is not always straightforward, that it takes time and, as I will discuss further in Chapter 4, requires the researcher to be constantly sensitive and adaptive to the needs and priorities of everyone involved and to the nuances of the research environment. In all, I formally presented the consent form to 83 patients and two visitors. Table 3.3 details the number of patients and visitors who gave written consent.

Table 3.3: Number of Patient and Visitor Participants by Type of Consent

Number of participants (total)	Consented to interview only	Consented to video only	Consented to interview and videoing (no reflexive component)	Consented to interview and videoing, and participated in video-reflexive session(s) (co-researchers)
Patients (27)	10	6	3	8
Visitors (2)	2			

Seventeen of these patients were colonised or infected with MRSA at the time of the study and were source-isolated in single rooms. One patient had recently been cleared of MRSA but remained in an isolation room. Another patient had recently been identified as colonised with MRSA but was unaware of this status on the day of her interview. The remainder had, to their knowledge, never experienced HAI. The two visitors who took part in an interview were the father and daughter of a patient who had acquired MRSA during her hospital stay.

Patient co-researchers

Several of the patients who participated in the research became co-researchers. They were people who maintained active interest and ongoing involvement in the research through to the time of this thesis submission. The kind of involvement varied from person to person. Gary, for instance, wrote and delivered conference presentations with me. Gary was also co-author on one of the articles in this thesis (Wyer, Iedema, et al., 2015) and Destiny is in the process of co-authoring a paper with me. Most co-researchers (but not all) were involved in video-reflexive sessions and then continued to meet with me one-on-one regularly to discuss the research findings to-date and other general IPC matters. I discussed earlier in this chapter how we would meet in the cafeteria, at outpatient appointments or when they were re-admitted as inpatients. Many times we would have conversations via phone if we had not managed to see each other face to face for a while. We formed relationships of mutual regard and friendship that I believe contributed to a richer research experience and outcome for us all.

3.5 Data creation and analysis

In Table 3.4, I detail the methods used in this study, which involved collecting approximately 300 hours of ethnographic observations, 11 hours of video footage, 27 patient/visitor interviews and 14 reflexive sessions (eight with patients and six with nurses). Although these methods are described in the table as three separate phases, they were rarely carried out in a linear fashion. For example, I spent my very first day of fieldwork talking to patients and handing out information sheets before videoing the point prevalence study the next day and then conducting video-reflexive sessions with patients the day after that. Following this was a month-long period of field observations and interviews before another patient video-reflexive session took place. Then there was a two-month return to field observation and interviews before the first nurse reflexive session took place. Thus, data creation and analysis were

intertwined, iterative, cyclical and moved back and forth across the phases set out below (Carter, 2010).

Table 3.4: Study Phases

Phase	Process	Procedure
Phase I	Field observations	Field observations were carried out from March 2013 – April 2014. Observations centered on IPC moments that occurred during everyday work.
	Interviews	Interviews with 21 patients and 2 family members. Some patients participated in follow-up interviews. 27 interviews in total were audio- and/or video-recorded and transcribed (121 minutes of video footage collected). Common themes were identified from phase I data by the researcher, patients and the research project team, to inform phase II of the study.
Phase II	Videotaping care	14 patients, eight female and six male, agreed to filming episodes of care (145 minutes of footage).
	Video-reflexive sessions with patients	8 of the 14 patients (4 female/4 male) took part in reflexive sessions (20-30 min). Six had experienced colonization or infection with methicillin resistant <i>Staphylococcus aureus</i> (MRSA). Footage of their care episode was shown to them to stimulate discussion of their understandings and strategies around IPC. 4 patients agreed to have these sessions video-recorded (141 minutes of footage); the others were audio-recorded.
Phase III	Video-reflexive sessions with staff (VRS)	Clips and quotes from phase II that demonstrated patients' understandings, strategies and concerns were chosen (by patients and researcher) as feedback for six group reflexive sessions with nurses. Sessions were held on both day and night shifts, with a total of 35 nurses (2 infection control practitioners (ICPs), 2 clinical nurse educators, 3 clinical nurse consultants and 28 ward nurses). The researcher facilitated these sessions asking nurses to respond to patients' insights and concerns; consider roles that patients might play in IPC; and how they could facilitate PI in IPC.

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Equipment

All interviews and video-reflexive sessions were audio-recorded on a digital recording device. The exceptions were one interview with a patient who spoke English as a second language and requested an interpreter who asked not to be recorded. One other patient also requested not to be recorded. Written notes were taken during these interviews. One patient, who could not speak, scribed his dialogue, which I then read aloud to the video recorder.

For video work, I used a small consumer-level digital camera with a flip-out viewing panel so that participants and I could review the footage immediately after videotaping if needed. One of the options for involvement on the consent form was for patients to keep a camera and make

a video diary of their infection control experiences. None of the patients chose this option. Most patients proposed that I control the camera when recording the footage, although James suggested that I set the camera up on a tripod in his room to gain a wide shot of his room.

During videoing of care, I usually held the camera by hand so that I could move around to prevent interference with the procedure taking place as well as allowing me to quickly zoom in or capture wider angles. If someone came into shot for a short period and did not wish to be videoed I would dip the camera to the floor until they left. If this person was likely to be involved in the interaction for a longer period I would endeavour to keep them out of shot or switch the camera off.

When patient reflexive sessions were video-recorded, I set the camera up on a tripod so that both the patient and myself were in shot. The reasons for this are described in Chapter 4. All nurse reflexive sessions were video-recorded. The camera was placed on a tripod and positioned to capture as many people as possible in frame, including myself.

Phase I – ethnographic field observations and interviews

Ethnographic methods such as observations and interviews are useful for gaining contextualised understandings of people's behaviours and how they make sense of those behaviours (Hammersley & Atkinson, 2007). As healthcare research begins to acknowledge context as a major factor in the successful uptake of evidence-based findings, ethnographic methods have been recognised as a useful approach to studying patient safety (Dixon-Woods, Leslie, Bion, & Tarrant, 2012; Leslie, Paradis, Gropper, Reeves, & Kitto, 2014). In my study, I used ethnographic observations to generate 'thick description' (Geertz, 1973) of the surgical unit and the people who inhabited it, but my observations and field notes were not used as primary data for formal analysis. Rather, during this phase I took on the role of 'clinalyst' (Iedema & Carroll, 2011) – by observing and shadowing nurses and patients and by asking

questions about how and why people did the things they did, I aimed to understand which infection control practices they felt were working well, which required attention, and therefore what could be a focus for videoing. I also relied on these collaborative explorations of practices to develop research relationships that would afford enough trust for people to engage in VRE with me. At the same time, I was also unavoidably making my own assessments about people and practices. For example, as a nurse I sometimes noticed infection control practices that I wanted to discuss or video with patients, and as I got to know individual nurses and patients, I gained a better sense of who might be open to taking part in the research.

As mentioned earlier, many patients did not wish to be videoed and opted to participate only in an audio-recorded unstructured interview²⁸ (Patton, 2002)²⁹. With the patients' permissions and input, several excerpts from these interview transcripts were fed-back to the nurses as quotes during nurse-reflexive sessions. I believe that these quotes lacked the same affective impact as showing video of care practices alongside patients' insights of these practices. Nevertheless, these more familiar methods served as a more 'comfortable' vehicle for these patients' to voice some of their understandings and enactments of infection control to the nurses who cared for them and were important for informing new directions for the research.

My approach to these ethnographic methods was therefore in keeping with the interventionist nature of my research, in that, through collaborative questioning and reflection, I did not seek to collect objective descriptions of practices from patients and staff. Instead, I treated these data as "partial, incomplete, and [...] always in a process of a retelling and remembering"

²⁸ The participant information and consent form refers to the interviews conducted with patients during this study as 'semi-structured'. However, the interviews that actually took place were more unstructured. Allowing for the spontaneous generation of questions that occur during the natural flow of a conversation (Zhang & Wildemuth, 2009).

²⁹ Two of the patients participated in an interview that was videoed at the bedside. Footage of their interviews was used in reflexive sessions with nurses.

(Jackson & Mazzei, 2013, p. 262). Furthermore, I was aware that my interactions with participants could also affect ways of thinking about these practices. Mesman (2007) describes the transformative spaces that are created when participants and researchers “interact as reflective practitioners” during ethnographic research (p. 283). These can be considered as:

Spaces in which [researchers] explicate [participants] hidden competences and question (breach) their dominant ways of understanding patient safety. These forms of intervention aim to increase their ‘safety sensibility’ and to offer alternative images of patient safety (p. 283).

In this way, my very presence as a researcher interacting with people and the environment was itself an intervention that could kindle a process of analysis of practice for participants. In turn, their responses and reactions affected me and prompted me to think in new ways in my research.

The process described above emphasises my goal to promote the agency of participants as co-researchers. I did, however, also apply more traditional analyses to my interview data. Both the patients and I wanted their voices to be heard by audiences outside of the ward environment, and academic publishing was one way of doing this. Publishing in the area of health sciences requires alignment with formats and procedures that do not always provide much scope for novelty although I endeavoured to maintain patient involvement in the process. The recorded interviews were transcribed and entered into Dedoose qualitative software. I initially identified a range of themes and subthemes through careful reading of the transcripts, which I then discussed with patients who were interested, as well as the wider NHMRC project team. Through this collaboration, the themes were refined over time, and form the basis of the paper found in Chapter 5. One of my patient co-researchers, Gary

Armstrong, was particularly involved in this process and became a co-author on this paper. Despite the calls for greater patient involvement in infection control, this paper could not find a home in the several infection control journals it was submitted to. It was eventually published by the *Patient Experience Journal*.

Phase II – video ethnography and reflexive sessions with patients

Earlier in section 3.4, I described the processes by which I recruited patients, and the kinds of care that were videoed during this phase. In the sections below, I elaborate on how patients and I progressed from videoing to the video-reflexive sessions. I describe below the three types of scenarios that were videoed and then shown back to patients in reflexive sessions.

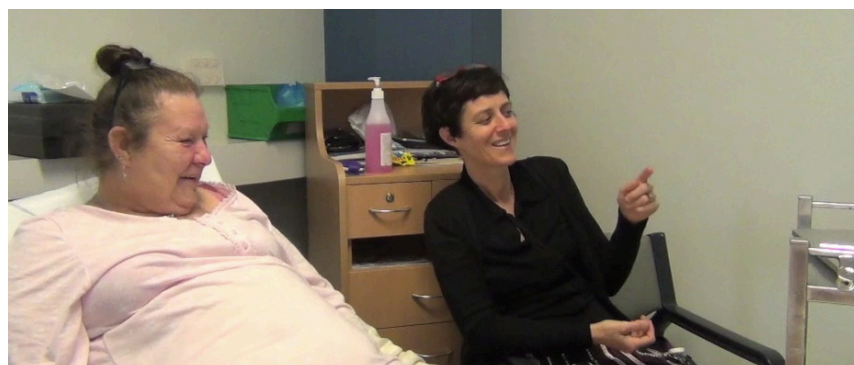
Point prevalence study

The first series of care interactions I videoed was the point prevalence survey described above, during which the team of ICPs attempted to take MRO screening swabs from all 66 patients on the unit, which took more than four hours to complete. By the end of the survey, I had videoed 12 of the patients having their noses swabbed. After collecting all the written consents, I downloaded the footage to my laptop and showed it to the ICPs to gain their consent for showing it back to patients. It was then too late in the day to commence reflexive sessions although my intention had been to do both videoing and reflexive sessions on the same day.

The following day, I returned to do the reflexive sessions. Of the 12 patients videoed, five were discharged before a reflexive session could take place. One patient had become quite unwell overnight and withdrew from the study. I conducted reflexive sessions at the patient's bedside with five of the remaining patients over the next two days. The sixth session was recorded later in a hospital tutorial room. In most VRE studies, there are analytical choices to be made about selecting footage to be shown back to participants, but in this part of my study,

I played back the footage in their entirety to the patients, as each individual clip was only one to two minutes long. I positioned the laptop so that both the patients and I could view it. Usually the patient was in or near their bed and I sat on a chair next to them with the laptop on a table or trolley in front of us (see figure 3.1).

Figure 3.1: Reflexive Session at Bedside



I played the video a few times, with sound at first and then without sound, so that the patients and I could discuss and interpret the footage together. Initially, I invited participants to comment freely on what they saw with regards to infection control. If patients struggled to initiate dialogue, I asked them questions such as: *From your perspective what is happening here? What were you thinking/feeling when the swab was being taken? Why do you think they took the swabs?* The *hologrammatic* effect of the video often stimulated patients to talk about incidents and feelings related to events both on and off the screen. Each session lasted about 20-30 minutes. Four of these sessions were audio-recorded and two were videoed.

General bedside activity

James became aware of my study when he was involved in video recording for the clinician project. He asked to meet me and agreed to an audio-recorded interview. After this interview, he suggested we set up a camera in his room and video some of the morning routines in his isolation room. We did this one week later. James and I sat in screen shot discussing IPC, and when clinicians or other healthcare workers entered the room we informed them that the

camera was recording and asked for their consent to video their interaction with the patient. If they refused, the camera was switched off. The clinicians who agreed to be videoed were asked if they would like to review the footage before James and I watched it back together but they declined. I downloaded the footage onto my laptop and James and I watched back one particular healthcare interaction that had taken place that we were both interested in. In this footage, we witnessed a scene where a number of people were all engaged in different activities inside the isolation room: a phlebotomist taking blood, a nurse preparing medications, a meal attendant (mostly off screen) delivering lunch, and myself trying to collect consent forms. This reflexive session lasted 31 minutes and was video-recorded.

Wound dressing

June was told about my study by another patient who had been interviewed. She asked if I would interview her and this took place shortly before she was discharged. About six weeks later, June was re-admitted and this time she suggested we video her leg-wound dressing change. We sought and gained consent with her nurse who agreed to be videoed while carrying out this procedure. I stood at the head of the bed videoing down towards June's leg and the dressing trolley that was placed near the end of the bed. We videoed the dressing from beginning to end and the three of us discussed some aspects of the dressing while it was taking place. I downloaded this footage to my laptop and watched it with June at her bedside. This reflexive session lasted 40 minutes and was video-recorded.

Choosing footage and creating clips for feedback to nurses

After each patient reflexive session I asked patients if there was anything in particular that they would like fed back to the nurses and made a note of these requests. I then downloaded the audio or video recording onto my laptop. I then transcribed the session and entered it into Dedoose qualitative data analysis software. Initially I analysed this data using my research

questions to guide the process. I did this with three goals. The first was to identify the main issues that were important to patients and could be explored further in subsequent interviews, videoing and reflexive sessions. The second was to identify the main themes and subthemes in the patients' reflexive sessions that eventually (once all reflexive sessions were completed) informed the empirical paper found in Chapter 6. I discussed and refined these themes throughout the research with patients who were interested in doing so, as well as the NHMRC project team members.

The third goal was to identify quotes and clips that might be fed back to the nurses during their reflexive sessions. I selected these, prioritising the suggestions made by patients at the end of their reflexive sessions, but also drawing on my own clinical expertise and experience, as well as the issues and insights I identified as common across all reflexive sessions. All raw video data was transferred to the software program iMovie. First, I edited the raw data of the care episodes into short clips. Then I edited raw video data of patient reflexive sessions into clips of one or two minutes duration, based on the analysis described above. Most patients took the opportunity to review these clips and make decisions about what was most important to feed back to staff. In any case, I always sought verbal consent (despite having written consent) before showing any patient footage to anyone else. I also sought the permission of any staff member who appeared in the clips.

Phase III – video-reflexive sessions with nurses

The dates, times and places that the nurse reflexive sessions took place are shown in Table 3.5. Ward reflexive sessions were arranged through the clinical nurse educator. Because of the busy nature of ward work, nurses would enter and leave the reflexive space throughout the session if they needed to attend to a patient.

Table 3.5: Staff Reflexive Schedule

Reflexive session	Date	Participants	Time of day/ location	Attendance	Length (min.sec)
1	June 12, 2013	Infection control practitioners (ICP)	Afternoon ICP office	2	19.24
2	June 18, 2013	Ward nurses	Afternoon Nurses tearoom Ward A	18	47.07
3	July 26, 2013	Ward nurses	Night shift Nurses station Ward A	3	26.43
4	July 26, 2013	Ward nurses	Night shift Nurses station Ward B	3	59.15
5	Aug 12, 2013	Ward nurses	Afternoon Nurses tearoom Ward B	11	36.24
6	Sep 19, 2013	Ward nurses	Afternoon Nurses tearoom Ward A	7	38.18

With the consent of participants, I videoed these sessions. I placed the camera on a tripod in a position where the angle would capture as many people as possible in the room as well as the footage on the screen. Dr Hor, the senior researcher, was usually present at these sessions and assisted with the camera, shifting the focus when necessary and ensuring it was recording.

Most of the nurses were aware of my activities with patients and I had taken special care to be transparent and honest with them. I always checked with the nurse caring for a patient before proceeding with an interview or reflexive session and if they asked questions, I answered to the best of my ability, without breaching any patient confidence. This was done out of respect for the busy ward staff, but also in an effort to build and maintain research relationships that would keep nurses open to listening to what patients had to say during reflexive sessions. At the beginning of each session, I recapped the purpose and activity of the patient project, and that I wanted to share and discuss patients' insights with them. I made clear that all of the patients involved in this study had conveyed their overall appreciation of

the care they received, but that sometimes there were aspects of care that were distressing or confusing. I appealed to the nurses to welcome the patients' comments as learning opportunities for improvement rather than as personal criticism. To facilitate this, I also balanced clips in which patients were more critical of practices, with more positive or neutral accounts.

Using Microsoft PowerPoint slides, I usually presented footage of a care practice followed by footage or quotes (from interview transcripts) of patients commenting on that practice. Sometimes I presented a collage of clips and quotes related to a theme, such as glove use. I had several clips and slides ready to show at each reflexive session but how many were shown depended on the length of reflexive discussion that followed each one. Again, the *hologrammatic* effect of the video inspired discussions about broader issues related to those seen and heard on the screen. At the end of each session, I asked the nurses if there was anything already discussed by the patients, or if there was anything else, that they would like to hear about in the next reflexive session.

After each nurse reflexive session, I downloaded the footage onto my laptop, transcribed the discussion and explored the text for prominent and recurring themes. Clips for the next reflexive session were prepared based on these themes as well as on patients' and nurses' specific requests. A final feedback session was held toward the end of the first stage of the project that brought together the repeated and/or contested topics and the suggestions that had been discussed by the nurses over all of the reflexive sessions, with a view to planning action on solutions. I had hoped that the two nurses managers would attend this session so that they could assist in facilitating changes. However, despite repeated invitations, the managers did not attend any sessions. I offered to provide a private reflexive session that would fit in with

their schedule and although they agreed to this they could not commit to a time and it never eventuated.

3.6 Ethics and data storage

Ethics

I commenced my PhD in March 2012 at the University of Technology, Sydney (UTS). Prior to my commencement, formal ethics applications for the larger project had already been approved by Human Research Ethics Committees (HREC) from UTS³⁰ and the Western Sydney local health district (WSLHD)³¹. In October 2012, I applied to the WSLHD HREC for an amendment to include patients more actively in the research. This included changes to the consent form (see Appendix D & E) and the protocol, as well as the development of a media release form (see Appendix F) to be used if patients or staff agreed to photos, video or audio being used in publications or at conferences. Written approval was received on February 8, 2013. My study was then ratified through the UTS HREC.

In July 2014, my supervisor, the NHMRC project, and I transferred to the University of Tasmania (UTas). I updated the ethics documents to reflect this change with the HREC committees and applied for ratification with UTas, which was granted December 4, 2014³².

When research methodologies fall outside of the norms and limits of a discipline it can be difficult to obtain ethics approval (Iedema, Allen, Britton, & Hor, 2013). It can be especially problematic in healthcare research that involves videoing patients. Although it provides an excellent method for patients to be seen and heard, video also raises issues of privacy and anonymity (Harte, Homer, Sheehan, Leap, & Foureur, 2015). I was lucky in my research to be associated with an experienced research team who had a long history of respected work

³⁰ Approval number: UTS HREC 201-265

³¹ Approval number: HREC/2012/3/4.9 (3278) AU RED HREC/11/WMEAD/34

³² Approval number: H0014583

using video in healthcare and I had no problems obtaining ethics approval. However, I did heed advice from those who had gone before me, especially Aileen Collier who used an indigenous research ethics framework to guide her work with patients (Collier, 2013). Collier applied the principles outlined in the Australian Guidelines for Ethical Research in Australian Indigenous Studies (Australian Institute of Aboriginal and Torres Strait Islander Studies, 2012) to her work with people at the end of life, to ensure that patients remained central to the research, and that research was carried out in a participatory, respectful manner that was beneficial to patients (Collier, 2013). I was also influenced by Carroll's feminist approach to the power relations inherent in the use of VRE (Carroll, 2009a) as well as the International Visual Sociology Association Code of Research Ethics and Guidelines (Papademas, 2009). Further consideration of how I developed my own ethical approach when using VRE in new ways with patients is explored in Chapter 4.

In the recruitment sections of this chapter, I explained the process of obtaining written consent for participation in the project. To elaborate, participants were always informed of the voluntary nature of participating in the research and their right to withdraw at any time. Following written consent, a continuous consent process was adhered to. I always verbally asked for permission to video care or reflexive sessions, and participants could ask for the video to be stopped at any point. If patients signed a media release for use of footage at conferences or in academic publications, I would, as a courtesy, contact them and ask for verbal permission before each use of their images. Eventually, some patients gave blanket permission to use the footage in any way I wished and requested that I not contact them about this matter. As part of the consent process, patients were asked if they would like to be updated on the research progress. Many accepted this offer and I sent out regular updates via email and text. At first, these were delivered every few months and now I send out a yearly update.

I discussed the option for blurring of footage or photos with participants. None of the patients wanted me to do this, stating that they wanted to be seen and heard. Each patient chose her or his own pseudonym, or in some cases asked to have their actual name used. Some academic journals did not allow this, however, and asked for faces of patients to be blurred and for pseudonyms only to be used. All nurses' images have been blurred either at their request or if I could not contact them for their consent.

Data Storage

Transcribed interviews, audio-recordings, video-recordings and edited video clips were filed and stored on a password-protected computer. Field notes, consent forms and back-up hard drives were stored in lockable cabinets on the university premises. These will be securely stored for at least 5 years after the completion of this thesis. After this, data will be retained or destroyed according to current university and NHMRC guidelines.

3.7 Conclusion

This chapter has detailed the philosophical and theoretical underpinnings of the VRE methodology. A description of how VRE research has been used in healthcare research to date was provided as well as an explanation of how my research seeks to extend VREs methodological scope by inviting patients and visitors to take a more active role in the research. My research design provided significant potential for patient-centred practice change, but it also presented a number of challenges in the field. The following chapter explores these potentials and challenges.

Chapter Four Methodological Findings: Researching Reflexively with Patients and Families

Collier, A., & Wyer, M. (2016). Researching reflexively with patients and families: Two studies using video-reflexive ethnography to collaborate with patients and families in patient safety research. *Qualitative Health Research*, 26(7), 979-993. doi:10.1177/1049732315618937

4.1 Publication: Relevance to Thesis

This chapter is an adjunct to the research methods and approach to the study presented in Chapter 3 and focuses on the considerations and strategies for using VRE to research with patients. Prior to my fieldwork, the co-author on this paper and I discussed some of the potentials and challenges she encountered when using visual methods with patients at the end of life. She referred to these as ‘methodological findings’. In this paper, I discuss the different potentials and challenges I faced when attempting to use VRE in new ways and, in conjunction with my co-author, offer suggestions for a reflexive practice that others undertaking similar research might find useful.

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4.2 Conclusion

This shared some of the potentials and challenges I found using VRE with patients in ways that had not been explored previously. These included: building trust and equal research relationships with patients in short time frames; negotiating what would be videoed and who would see the resulting footage; and creating safe spaces for clinicians to ‘hear’ patients’ perspectives on the care they receive. The paper concludes that iterative and multilayered researcher reflexivity in the field is critical to the progress and success of studies seeking to use VRE with patients. The following chapter presents the first published paper of the research findings.

Chapter Five Should I Stay or Should I Go? Patient Understandings of and Responses to Source-Isolation

Wyer, M., Iedema, R., Jorm, C., Armstrong, G., Hor, S., Hooker, C., Jackson, D., Hughes, C., O'Sullivan, M., & Gilbert, G. L. (2015). Should I stay or should I go? Patient understandings of and responses to source-isolation practices. *Patient Experience Journal*, 2(2), 60-68.

5.1 Publication: Relevance for thesis

The paper presented in this chapter provides an introduction to the hospital unit where this research took place. It also gives prominence to the voices of patients who did not wish to be involved in video-reflexivity during the study. Even though I was able to engage with patients early on in the research using VRE, I also spent time talking to and interviewing patients and families, and observing IPC practices. Because of the high transmission rates of MRSA at the study site at the beginning of the study³³, many of the participants in my research had acquired an HAI on this, or on previous admissions. Therefore, many of the interviews (and video-reflexive sessions) took place in isolation rooms and conversations naturally turned to patients' experiences and understandings of source-isolation as an IPC practice. This paper examines this one particular strategy for IPC from patients' perspectives and then links their experiences and understandings to their actual IPC behaviours. Because of a lack of clinician-patient conversations about HAI and IPC, patients had limited understandings of precautions they should take and were engaging in behaviours that were potentially contributing to environmental MRO contamination. The paper argues that patients need to be involved as active participants in reducing infection transmission.

³³ The first point prevalence study in March 2013 showed an MRSA colonisation rate of 42%. Over the course of the wider NHMRC project this rate fell to 14%. Although there were other IPC activities happening in the unit at the time (e.g. hand hygiene audits, environmental cleaning) changes in colonisation and infection rates correlated most closely with the timing of the VRE projects (clinician and patient).



2015

Should I stay or should I go? Patient understandings of and responses to source-isolation practices

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5.2 Conclusion

This chapter presented an argument for involving patients as active partners in reducing infection transmission. It showed that, at this study site, conversations between patients and clinicians about HAI and IPC were scarce and that this left patients with limited understandings of how to keep themselves and others safe. In the absence of guidance from clinicians, some had developed their own creative strategies for reducing transmission. Others were unwittingly and sometimes deliberately engaging in activities that were potentially contributing to pathogen transmission. In all, this paper highlights the consequences of clinicians neglecting patients' activities that can impact upon IPC. In the next chapter, I explore what can be achieved by actively engaging with patients IPC activities and insights using VRE.

Chapter Six Involving Patients in Understanding Hospital Infection Control Using Visual Methods

Wyer, M., Jackson, D., Iedema, R., Hor, S., Gilbert, G. L., Jorm, C., . . . Carroll, K. (2015). Involving patients in understanding hospital infection control using visual methods. *Journal of Clinical Nursing*, 24(11-12), 1718-1729. doi:10.1111/jocn.12779

6.1 Publication: Relevance for thesis

To my knowledge, this is the first study to invite patients to identify and discuss patient safety risks they observed in videoed care. This paper describes how using VRE with patients supported patients to come to better understandings of IPC practices, how they can have their IPC needs better met, and the roles they can and do play in reducing infection transmission.

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6.2 Conclusion

This chapter demonstrated that by scrutinising video footage of real time *in situ* practices, patients were able to recognise previously unidentified infections risks and habituated behaviours around IPC, and were motivated to develop new ways of having their IPC needs met. Through this process, the patients and I became more aware of the roles patients can and do play in reducing infection transmission, as well as the barriers they face trying to enact these roles. The next chapter explores how nurses caring for these patients were affected by, and responded to, video feedback of patients' analysis of care.

Chapter Seven Patient Involvement can Affect Clinicians' Perspectives and Practices of Infection Prevention and Control

Wyer, M., Iedema, R., Hor, S., Jorm, C., Hooker, C., & Gilbert, G. L. (2017). Patient involvement can affect clinicians' perspectives and practices of infection prevention and control: A "post-qualitative" study using video-reflexive ethnography. *International Journal of Qualitative Methods*, 16(1). doi: 10.1177/1609406917690171

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7.1 Publication: Relevance for thesis

The previous chapter put forward the argument that clinicians should actively engage patients in conversations about IPC practices and pay attention to patient feedback about infection and infection risk. It is clear from the wider patient involvement in IPC literature and from my study, however, that these kinds of conversations rarely occur. In the following paper, I describe how I extended the application of VRE to negotiate new ways for clinicians and patients to relate and communicate around infection risks and IPC practices.

Article

Patient Involvement Can Affect Clinicians' Perspectives and Practices of Infection Prevention and Control: A "Post-Qualitative" Study Using Video-Reflexive Ethnography

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Abstract

This study, set in a mixed, adult surgical ward of a metropolitan teaching hospital in Sydney, Australia, used a novel application of video-reflexive ethnography (VRE) to engage patients and clinicians in an exploration of the practical and relational complexities of patient involvement in infection prevention and control (IPC). This study included individual reflexive sessions with eight patients and six group reflexive sessions with 35 nurses. VRE usually involves participants reflecting on video footage of their own (and colleagues') practices in group reflexive sessions. We extended the method here by presenting, to nurses, video clips of their clinical interactions with patients, *in conjunction with* footage of the patients themselves analyzing the videos of their own care, for infection risks. We found that this novel approach affected the nurses' capacities to recognize, support, and enable patient involvement in IPC and to reflect on their own, sometimes inconsistent, IPC practices from patients' perspectives. As a "post-qualitative" approach, VRE prioritizes participants' roles, contributions, and learning. Invoking affect as an explanatory lens, we theorize that a "safe space" was created for participants in our study to reflect on and reshape their assumptions, positionings, and practices.

Keywords

affect theory, video-reflexive ethnography, infection prevention and control, healthcare-associated infection, patient safety, patient involvement, collaborative research, post-qualitative methodology

What is already known?

Patient involvement is increasingly recognized as critical for improving patient safety, but how clinicians realize higher levels of patient involvement in everyday care still remains contested and uncertain. Few patient involvement approaches move beyond improving clinicians' listening to patients, and still fewer approaches actively seek to realize patients' input about care practices into existing kinds of clinical work and clinician behaviors.

What this paper adds?

This paper takes the following principle as its point of departure: patients can teach clinicians about complex healthcare practices in general, and about infection control in specific. Theoretically, this paper promotes affect as a critical resource for gaining traction with the practical and relational complexities of patient involvement in infection prevention and control.

Methodologically, the paper demonstrates that video-reflexive ethnography affects participants, enabling frontline clinicians, patients as well as researchers to grapple in new ways with how to realize patient involvement in healthcare.

The healthcare improvement literature is increasingly acknowledging the value, for reform, of the experiences and

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insights of patients and their families (henceforth referred to as “patients”). Studies have shown that patients have unique and valuable knowledge of, and insight into, the quality and safety (or lack thereof) of care processes that affect them (Weingart et al., 2005; Weissman et al., 2008) and are able to articulate important insights about how to redesign services and processes (Iedema, Allen, Britton, & Gallagher, 2012). It is also known that patients’ active involvement in clinical safety initiatives can improve clinician adherence to safety practices (Bittle & LaMarche, 2009; McGuckin & Govednik, 2013).

That said, patient involvement in clinical safety is likely only to be effective when valued, supported, and encouraged by clinicians (Coulter & Ellins, 2007; Hrisos & Thomson, 2013). The literature suggests that while clinicians accept, in theory, that patient involvement may help improve services and reduce adverse events, they tend to have limited knowledge about how, and to what extent, to implement it (Martin, Navne, & Lipczak, 2013; Seale et al., 2016). Clinicians also appear to gravitate toward forms of patient involvement that align with more traditional patient roles, such as patients checking their medications, rather than activities that expand the patient’s role, such as patients reminding staff to wash their hands (Davis, Briggs, Arora, Moss, & Schwappach, 2014; Hrisos & Thomson, 2013).

To some extent, however, these conclusions cannot be dissociated from the methodologies deployed to produce them. Put differently, what we know about patient involvement reflects the ways in which it has been studied. In the case of infection prevention and control (IPC), which provides the empirical context for this study, clinicians’ attitudes to patient involvement have been measured using interviews (e.g., McInnes, Phillips, Middleton, & Gould, 2014) and self-reported attitude surveys based on hypothetical scenarios (e.g., Davis et al., 2014; Kim et al., 2015). These methods, although undeniably useful and valid, obtain their data at one or more removes from in situ care interactions unfolding in complex environments. Such data therefore may not adequately account for attitudes and understandings that are multidimensional, situational, and can involve practical tensions and contradictions.

Similarly, these methods shed little light on how patient involvement is enacted locally. In cases where patient involvement in IPC has been actively facilitated, for example, by encouraging patients to remind healthcare professionals about their hand hygiene, its traction tends to be accounted for in terms that are abstract and generalizable. For instance, the impact of patient involvement has been measured through soap/sanitizer usage, hand hygiene adherence, and pre- and post intervention surveys (Davis, Parand, Pinto, & Buetow, 2015). These data and analyses are important for assessing general improvement in processes and attitudes but, in isolation, do not indicate why it has occurred or what practical changes are needed to sustain it.

To address patient involvement adequately, we need to be able to situate it amid the complexities of mounting demands placed on healthcare professionals resulting from rising numbers of (older) patients with increasingly complex disease

patterns and comorbidities, relentless staff and organizational churn, ongoing technological change, growing regulatory and policy pressures, and hardly abating political–interprofessional tensions (Dekker, 2012; Vincent & Amalberti, 2016). We therefore need innovative methodologies that focus less on measuring the impact of ideal world prescriptions and more on engaging with “real-world” challenges and opportunities. Such an approach raises the possibility of study results having practical significance for the people and phenomena investigated (Iedema, Mesman, & Carroll, 2013; Vincent & Amalberti, 2016). The present study is situated within this latter real-world paradigm (Iedema, 2011). This study was designed to engage with local complexity as experienced by patients and frontline practitioners, aided by video footage capturing aspects of that complexity. We aimed to investigate whether local complexity might be rendered tangible, discussable, and manageable, by involving local stakeholders in reflecting on footage portraying their care practices.

Prioritizing Complexity and Affect in Patient Involvement Research

A common method for answering calls for patient involvement is to collect patient feedback on their experiences of care through surveys and interviews, whether retrospective (Sutton, Eborall, & Martin, 2015; The Health Foundation, 2013) or current (Giles, Lawton, Din, & McEachan, 2013; Lawton et al., 2015). However, we also find methodologies that use face-to-face dialogue as a springboard for collaborative service design, notably “*experience-based codesign*” (EBCD; e.g., Larkin, Boden, & Newton, 2015). EBCD structures patient involvement as a dialogic process, making use of in situ, filmed, or transcribed interviews with patients (Bate & Robert, 2007). While different in principle and in orientation, surveys, interviews, and EBCD are nevertheless similarly constrained. Both rely on participants’ espoused and taken-as-given views of what happens or what should happen in care as the basis for measurement, decision-making, and redesign.

As Greatbatch, Murphy, and Dingwall (2001) have pointed out, what people know to say consciously may not fully or accurately account for what they and others enact or experience in situ. Hence, asking patients (or clinicians) to rate or talk about care will not exhaustively clarify “the practices and procedures through which [care] tasks and activities are accomplished in actual circumstances” (Greatbatch, Murphy, & Dingwall, 2001, p. 189). It is this gap between what people say they know and the more complex domain of actual in situ practice and experience that points to the limits inherent in relying on participants’ selected memories and espoused opinions. It is here that a new investigative paradigm, anchored in the *post-qualitative* turn (Lather & St. Pierre, 2013), may assist in bridging this gap.

Post-qualitative investigations identify in the first instance not with proceduralized data collection and standardized analysis. Instead, they take *affect* as their point of departure, requiring that participants (clinicians, patients, and researchers)

harbor “a capacity to affect and be affected” (Fox, 2015, p. 301). The rationale is that such capacity is deemed to be a prerequisite for grappling with and intervening in in situ complexity. Privileging objectivity and formal knowledge, few investigations in healthcare to date prioritize this affective capacity. We should acknowledge, however, that EBCD (referred to above) mobilizes patients’ experiences as an *affective* resource: Narratives or footage of patient interviews are used to entrain clinicians to consider changing their perspective on care and redesigning how they work (Bate & Robert, 2007). Narrative affects people by invoking in them a sense of being implicated, motivating them to respond and act.

Post-qualitative research prioritizes affect as a means of connecting us to the future. Unlike emotion, whose principal reference is the psychology of personal reactions, affect foregrounds agency (Brennan, 2004). Indeed, for affect theory, “the greater our power to be affected, the greater our power to act” (Hardt, 2007, Introduction, p. x). In other words, the more we are receptive to (or affected by) what goes on around us situationally (interpersonally, emotionally, politically, clinically, and practically), the more accomplished we will be as learners facing complexity and uncertainty (Dewey, 2007). As such, we become more effective as actors (Carroll, 2009).

Patient involvement is, at heart, an interpersonal and therefore an affective dynamic. Inevitably, involving people relies on more than a simple invitation to them to become involved. Rather, involvement is a complex dynamic process, the quality of which is likely to determine its duration and intensity. A post-qualitative research approach that harnesses affect to make complex dynamics such as these intelligible and amenable to intervention is video-reflexive ethnography (Iedema & Carroll, 2015).

Video-reflexive Ethnography (VRE)

VRE is an interventionist research approach that comprises video ethnography, the negotiated videoing of everyday naturally occurring work practices, and video reflexivity, group reflexive sessions wherein participants make sense of the footage they feature in (Iedema et al., 2013). It is a methodology anchored in the theory that people learn and change through being enabled to question and disrupt their habituated (taken as given) ways of being and acting, resulting in an emotional response that plays a pivotal role in learning (Dewey, 2007). VRE centers on collaborating with participants on the design of video projects, visual data gathering, and using the video footage to enable participants to scrutinize and reshape actual in situ care processes (Iedema et al., 2013). Research has shown that this process can enhance participants’ affective awareness of and practical agency amid the in situ sociomaterial complexities that define clinical care (e.g., Collier, Phillips, & Iedema, 2015). In the VRE literature, these enhancements have been enabled due to the simultaneous “distancing and presencing” effect of video feedback. While viewing filmed care brings into focus (“presences”) what is assumed to be known about the unfolding of practice, including its taken-for-granted or “learned-to-forget” aspects, it also has the effect of “distancing

and unhinging” the viewer from how they act. This simultaneity affects participants: It enables them to see themselves as others might (Carroll, Iedema, & Kerridge, 2008; MacDougall, 2005; Massumi, 2002). It is in this sense that viewing footage of work practices opens participants up to a “space of transformation” (Massumi, 2002), which can provide motivation for them to feel they can and *need* to co-construct new common futures (Iedema et al., 2013).

This last point underscores the potential of VRE to intervene in both the clinical–organizational and social-affective dimensions of care processes and healthcare relationships, insofar as footage of in situ activity makes tangible the “felt” dimensions of care as a social dynamic. This is the benefit of using video reflexively and collaboratively: People are likely to be affected by what they witness in the footage and by others’ responses (Iedema et al., 2013). Since patient involvement is essentially a person-to-person or a *relational* dynamic, we suggest that this special affordance of VRE may also assist the initiation and exploration of involving patients in the safety of their care. We also propose that the affective effect of video feedback might be enhanced when clinicians receive feedback from patients that they have recently, or are even currently, caring for. This shrinking of the patient/clinician feedback loop can offer rich feedback that is grounded in context and direct experiences and, as such, provides powerful impetus for learning and change (Dewey, 2007).

To date, VRE studies in healthcare have mainly focused on the activities and expertise of clinicians for improving patient safety (e.g., Carroll et al., 2008; Hor, Iedema, & Manias, 2014; Iedema et al., 2015). With a few exceptions (e.g., Collier et al., 2015; Wyer et al., 2015), patients are rarely actively involved. The present article reports on a study that mobilized VRE to intervene in the relationships between patients and clinicians in the critical area of the prevention and control of healthcare-associated infections (HAIs). HAIs are a major threat to patient safety, being a cause of increased morbidity and death among hospitalized patients worldwide (World Health Organization, 2011).

The Study

Study Approach

We first undertook VRE with hospital inpatients, by asking them to analyze footage of their own clinical care and to look for cross-contamination risks. Our rationale here was to acknowledge and respect patients’ expertise and contributions to their own safety, and to see whether this approach would enhance their agency, as it had for clinicians in previous VRE research (Iedema et al., 2013).

We then extended the VRE methodology by showing footage of patients’ analyses of their own care to clinicians. We did this by conducting group reflexive sessions with nurses in which clips of their clinical interactions with patients were presented *in conjunction with* footage of patients discussing the same interactions. In doing so, we sought to achieve the following methodological aims: (1) to explore further the complexities of patient involvement in IPC described earlier, (2) in



Figure 1. Study design phases.

a way that shrinks both the research/practice gap (Iedema & Angell, 2015) and the patient/clinician feedback loop, (3) by creating a space that includes the elicited expertise and perspectives of *both* patients and clinicians, through representing their own recent practices in their own ward, albeit mediated by the methodology (Collier & Wyer, 2016). More broadly, we sought to explore to what extent nurse participants, through being confronted with patients' responses to footage of clinicians caring for them, were able to modify their own enactments of IPC and, through this process, appreciate the productive possibilities of patient involvement to IPC.

Study Design

This article is based on a doctoral study that was part of a larger 3-year project, aimed at strengthening frontline clinicians' IPC practices (Iedema et al., 2015). The study took place in a 66-bed, adult surgical unit in a metropolitan teaching hospital

in Sydney, Australia, and focused on involving patients as active research participants in studying IPC practices.

VRE was carried out in three overlapping phases (see Figure 1 and Table 1). The first two phases used VRE to elicit and explore patients' understandings, experiences, and enactments of IPC. The study approach, including the negotiating and production of video clips, and the findings for Phases I and II have been detailed elsewhere (Wyer et al., 2015). Briefly, these findings provided hitherto unavailable insights into patient perspectives and enactments of IPC and engendered in patients a more critical attitude to transmission risks.

The focus of this article is on Phase III. Selected footage of clinical interactions and patients' commentaries on the same footage were presented to nursing staff during reflexive sessions.

After each reflexive session, clinicians' discussions were transcribed and analyzed for prominent recurring themes. Clips were prepared for follow-on reflexive sessions based on these themes, on patients' wishes for particular events to be raised with the nurses, and on nurses' requests for specific patient feedback. Finally, all reflexive session transcripts were further examined for repeated and/or contested topics, which in turn were presented and discussed with the nurses in a final feedback reflexive session.

Ethical Considerations

Human research ethics committees at the University of Technology, Sydney, the University of Tasmania, and the relevant local health district granted approval for this study. The process for obtaining patients' consent is explained elsewhere (Wyer et al., 2015). For the nurses, an iterative consent process was undertaken, with handouts distributed at project information sessions and consents for observation and videoing first obtained in writing and then verbally negotiated on each subsequent occasion. Participation was voluntary and the nurses could ask for videoing of reflexive sessions to be ceased at any time and could withdraw from the study at any time. In recognition of the potentially confronting nature of patients' comments, each reflexive session began with an outline of the purposes of the study, emphasis on patients' courage in raising IPC questions and concerns, and a repeat request for everyone's consent to be involved in the reflexive process.

Findings

The in situ complexities of patient involvement in IPC were explored in discussions throughout the nurses' reflexive sessions in two aspects: (1) the practical issues and implications of patient involvement and (2) the relational and affective dimensions of patient involvement. We share specific examples of each of these aspects below. This section also outlines the patient involvement and IPC strategies that were developed during the reflexive sessions.

By way of general background, during the initial stages of fieldwork, it became clear that nurses were frustrated at the significant levels of environmental contamination and methicillin resistant *Staphylococcus aureus* transmission in the ward.

Table 1. Study Phases.

Phases	Process	Procedure
Phase I	Field observations	Field observations were carried out from March 2013 to April 2014. Observations centered on IPC moments that occurred during everyday work.
	Interviews	Interviews with 21 patients and two family members. Some patients participated in follow-up interviews. Twenty-seven interviews in total were audio- and/or video-recorded and transcribed (121 min of video footage collected). Common themes were identified from Phase I data by the researcher, patients, and the research project team to inform Phase II of the study.
Phase II	Videoing care VRSs with patients	Fourteen patients, eight female and six male, agreed to filming episodes of care (145 min of footage). Eight of the 14 patients (four female/four male) took part in reflexive sessions (20–30 min). Six had experienced colonization or infection with MRSA. Footage of their care episode was shown to them to stimulate discussion of their understandings and strategies around IPC. Four patients agreed to have these sessions video-recorded (141 min of footage), the others were audio-recorded.
Phase III	VRSs with staff	Clips and quotes from Phase II that demonstrated patients' understandings, strategies, and concerns were chosen (by patients and researcher) as feedback for six group reflexive sessions with nurses. Sessions were held on both day and night shifts, with a total of 35 nurses (2 ICPs, 2 clinical nurse educators, 3 clinical nurse consultants, and 28 ward nurses). The researcher facilitated these sessions asking nurses to respond to patients' insights and concerns, consider roles that patients might play in IPC, and how they could facilitate patient involvement in IPC.

Note. VRS = video-reflexive session; MRSA = methicillin resistant *Staphylococcus aureus*; IPC = infection prevention and control; ICPs = infection control practitioners.

Many felt they were doing as much as they could to reduce transmission and that patients and visitors were major contributors to the spread of pathogens. These nurses believed that patients and visitors adhered inconsistently, if at all, to IPC measures despite having been given information from ward staff or infection control practitioners. It was against this background of assumptions and attitudes that footage was shown of patients from their ward commenting on the care.

The Practical Complexities of Patient Involvement—Glove Use

As the nurses watched footage of patients describing their own understandings of transmission risk and precautions, discussion around practical complications arose, relating to the informational needs of patients and staff and to confusion arising from variations in current IPC practice. One particular example was that of nurses' glove use. The nurses were surprised to discover that many patients said they felt safe only if gloves were worn for direct care (see Supplementary Video 1, e.g., or see transcript of this footage in Wyer et al., 2015). It was evident for the nurses, however, that in many of the videoed episodes of care, gloves were either not necessary or were being used inappropriately. The following excerpts are from discussions sparked by nurses' viewing of the footage of patients commenting on glove use (or lack thereof) during nasal swab screening for multidrug resistant organisms.

Nurse 27: From his perspective he just sees gloves and thinks, "Yeah I'm protected from infection because they're wearing gloves." But then he doesn't know whether or not people have washed their hands before they put the gloves on. So unless you wash your hands before you put gloves on, you may as well not have put your

gloves on...it's interesting that people feel safe when they see the gloves and gowns and things like that.

[...]

Nurse 27: It's interesting what they do notice actually and you don't think about it...when he knew that they weren't actually sterile gloves. He was happy to just have her wash her hands then.

[...]

Nurse 18: [He didn't know] the difference between sterile and gloves and clean gloves...we [should] properly explain to them which ones we're using.

[...]

Nurse 16: We can explain to them, "Yeah, I'm going to wash my hands." Instead of putting gloves on.

(Excerpt from video-reflexive session [VRS] #2)

Viewing footage of a routine ward practice, alongside patients' perspectives of that practice, evinced for these nurses a disconnect between their own and their patients' understandings of best practice for glove use. This raised previously unrecognized issues for these nurses: First, that patients in their ward did *not* receive adequate information about IPC, second, to compensate for nurses' lack of engagement with patients' needs around IPC, some patients were closely observing nurses' practices and developing their own understandings and strategies based on what they saw, and third, that nurses needed to be more attuned to the kinds of information patients need to feel safe and to engage in their own safe behaviors. This process led nurses to come to new understandings about the importance of initiating everyday, informal conversations with their patients about the rationale behind practices, rather than relying purely on



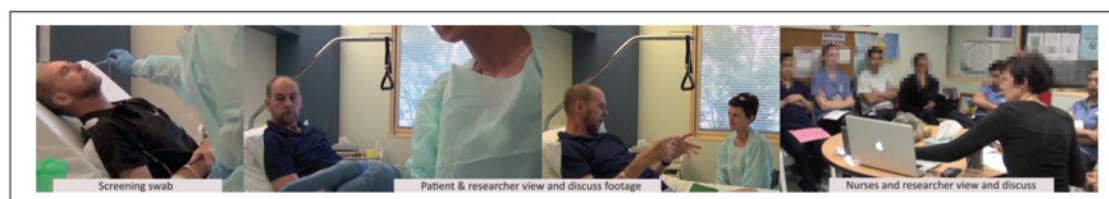


Figure 2. Reflexive process and discussion: Source isolation.

formal education sessions or written pamphlets. It was also recognized that this would do more than just reassure patients. In fact, involving patients more could assist everyone in the ward in their efforts to reduce infection transmission.

If you educate them then you empower them as well. So the more they know, the more they are able to prevent and be responsible for their own surroundings. (Nurse 7, VRS #2)

Viewing and reflecting on the footage *collaboratively* also served to reveal for the nurses that *they themselves* had different interpretations of what constituted appropriate or inappropriate uses of gloves:

Nurse 21: ...[for nasal swabs], it's still body fluids. ... So she has to wear gloves for that.

[...]

Nurse 13: For the nose, I wouldn't be wearing gloves. For the armpit too, I wouldn't be. But for the perineum, yes I would be wearing gloves.

[...]

Nurse 17: There is policy but there is also each nurse [with] a different interpretation of what the risk [is] and what the policy actually says.

(Excerpt from VRS #5)

These discussions highlighted that IPC rules can be confusing for staff as well as patients and that, as professionals, the nurses needed to be more consistent in their practices. Participating nurses subsequently sought more clarification from policy or from infection control practitioners. They also requested more video-feedback sessions on patients' understandings of glove use. In the following months, some nurses informed the researcher (personally and during other reflexive sessions) that they now paid more attention to their own and others' personal glove use, including the need to perform hand hygiene before putting gloves on, to question what type gloves should be worn, or if gloves were necessary for a particular activity.

The Relational Dimensions of Patient Involvement in IPC

A second theme centered on how the nurses confronted the affective dimensions of patient involvement in IPC. This section addresses how the nurses came to recognize interpersonal

barriers between themselves and their patients and how they went on to develop strategies to promote patient involvement.

Some of the patients who were involved in VRSs had experienced HAI and, as they watched the footage, they discussed their experiences and understandings of care practices that occurred in source-isolation rooms (see Figure 2 and Supplementary Video 2, e.g.).

The following excerpt is part of a discussion between three nurses watching footage of patients in source isolation. The reflexive process raised discussion around the barriers preventing nurses from discussing isolation precautions with patients, including their fears of offending patients, and of being abused by patients or visitors. The transformative effect of the affective space produced through VRE can be seen in the nurses' shifting views about why patients' might leave their source-isolation rooms, potentially spreading pathogens. It was recognized in this session that both patients and nurses face difficulty in speaking about and negotiating source-isolation practices and that nurses had a role to play in helping to inform patients about the implications of source isolation and to engage in these difficult conversations.

Nurse 3: We cannot stop them walking around, using our kitchen. They've been told [not to] but they're still doing it.

Researcher: Say you see someone walking [out of their source-isolation room] do you then go and tell them, "You're not supposed to be outside"?

Nurse 3: Oh, no... they would be offended if you do that but....

[...]

Nurse 31: They need to be informed. Because they don't know... the patient and their relatives, everybody. But who informs them?

Researcher: No one.

Researcher: So, who do you think should inform them?

Nurse 32: Well, I guess everybody.

Nurse 3: And the nursing staff too. We should start telling them... you know, in a way, it's not a jail—to keep them in the room. It's already depressing being in a single room.... It's not fair.

[...]

Nurse 32: When I ask [visitors] to do it... to use a like a gown, some of them they do use it, but some of them, they don't. Some of them just say it's not necessary. They might even turn around to abuse you.



- [...]
- Nurse 3: I think we need to have the courage to talk to the patients.
- Nurse 31: Yeah....
- Researcher: It sounds like it's a scary thing to do?
- Nurse 3: It's not like "scary" but....
- Nurse 32: Depends on how we present it.
- Nurse 3: The way you approach and the way is they're going to accept it....
- Nurse 31: The way...we don't want them to be....
- Nurse 3: ...offended....
- [...]
- Nurse 3: Like, in a way, we shouldn't be offended [if they question us]. Because it's their life, not our life. You know what I mean?
- Nurse 31: Yeah, yeah. They have rights too.
(Excerpt from VRS #4)

Nurses in a subsequent reflexive session also recognized the importance of their rapport with patients in having these difficult conversations, especially in allowing patients to feel comfortable initiating questions and discussions around IPC. For example, after watching Supplementary Video 2, the nurses noted that the patient's comments point to the quality of their relationship with patients and that this relationship determines whether patients believe they can have input into their care.

- Nurse 21: It depends on what kind of relationship you have with the nurse. Because...I have looked after him; he is very good with me. But a lot of other nurses...doesn't have the rapport. So he will probably ask me something that that he wouldn't ask someone like (Nurse 17). Because he doesn't get along with her.
- Nurse 17: Yeah, I think he is actually right. Like I admit it, I wouldn't be able to answer all of his questions.... But if he were to ask me, it would start the ball rolling and then I would go and search for the information that he needs...I guess probably [he didn't ask] because he didn't feel he had that rapport or was comfortable enough to ask.
(Excerpt from VRS #5)

The critical aspect of this excerpt is that it demonstrates that the nurses were beginning to articulate their sense that patient safety and patient involvement are significantly dependent on the affective quality and strength of their relationships. Through participating in VRE, the nurses came to realize that all patients (and not just those with multidrug resistant organisms) need to be given the opportunity to talk about infection risks and that they themselves needed to be proactive about communicating those risks to patients.

I think the best people will be first the Infection Control nurse...and then, as [ward] nurses we need to constantly be reminding them. (Nurse 13, VRS #2)

The nurse educator subsequently developed a ward-specific patient information folder for all patients to receive on admission that included information on HAIs and hand hygiene. In two of the reflexive sessions, the nurses discussed the possibility of developing an informational video that could play on the free to air TV channel. For some, this was seen as an audit compliance exercise, allowing them to "*tick a box somewhere saying that patient education toward infection control had been attended to*" (Nurse 27, VRS #5). Others hoped it would lead to more open communication between staff and patients about IPC.

Discussion

To our knowledge, this is the first study that has (1) provided patients with opportunities to comment freely on videoed clinical care interactions for infection risks and (2) fed back patients' insights to clinicians who care for them, for the purpose of occasioning learning. In doing so, this study created new ways of involving both patients and clinicians in IPC research, while respecting the complexity of everyday care interactions. By presenting footage of nurses' everyday work, alongside patients' observations of the same events, it was possible to shrink both the research/practice gap and the patient/clinician feedback loop, by enabling the nurses to link what they do in real time to how this matches their own espoused goals as well as how it matches the views and expectations of the patients on their ward. We found that nurses involved in reflexive discussion of patients' views and insights were able to identify and negotiate not only the practical but also the relational complexities of patient involvement. In doing so, broadening their capacity and appreciation of the benefits of involving patients in IPC.

Our research demonstrates how VRE can create a "transformative space" (Massumi, 2002) for patients, clinicians, and researchers. In a recent paper (Wyer et al., 2015), we described how, for patients, the reflexive process enabled more informed understandings of IPC, which prompted them to describe or develop new strategies for keeping themselves and others safe from infection. Furthermore, because they were invited to comment freely on footage of real-time care, patients could offer spontaneous insights or concerns about infection risk, rather than responding only to a *priori* identification of risks by researchers or clinicians. We have shown here how these spontaneous insights demonstrated, for the nurses who watched the footage, that patients were active, rather than passive, participants in IPC. Moreover, patients were now seen as actors who could recognize risks and practices that the nurses had taken for granted. Evidence that nurses were affected by patients' insights could be seen in their lengthy discussions on topics raised by patients and in requests for more patient feedback in future sessions.

The transformative reach of the VRE process for nurses viewing patients' analyses was also reflected in how their reflexive discussions were not limited to considering whether or not the patient was right or wrong about a practice. Instead, the nurses were able to consider broader issues around these topics and to

act on them. For example, the nurses' responses to patients' insights on glove use extended beyond discussions about "what is good practice" in the viewed clips, through to glove use during other activities, and to developing safer ways of practicing IPC and better ways to communicate with patients.

Critically too, the content of nurses' reflexive discussions indicated that more knowledge about IPC rules alone would not necessarily suffice to enable them to better educate patients or to partner with patients in reducing infection risks. The video-reflexive process created opportunities for nurses to confront and come to terms with not only the practical and technical but also the affective and relational dimensions of healthcare: the emotions and anxieties that affect how clinicians work, how clinicians and patients relate to each other, how they negotiate knowledge together, and how they position themselves in relation to one another. Important considerations here are patients' misunderstandings about IPC, their apprehensions about questioning clinicians' practices and confusions about practice variations, and staff fears of abuse, critique, and misunderstanding. That some nurses described the need to "be brave" in their clinical interactions, illustrates that clinicians, as well as patients, experience vulnerability around IPC care and communications.

Overall, the study highlighted the benefits of clinicians' becoming aware of their own vulnerabilities and differing stances and, with that, the promise of an emerging affective intelligence: the ability to codevelop effective responses to emergent circumstances. Going beyond "collective competence," enabling tasks to be accomplished thanks to people's resilience and vigilance, affective intelligence is critical to patients' safety as it broadens how people relate, respond, and key in to one another (Iedema et al., 2013).

Anchored in post-qualitative methodology, this VRE study provided space and time for such affective intelligence to emerge and be nurtured. Notably, the nurses' responses and discussions demonstrated that they were beginning to come to terms with their patients' and their own assumptions and concerns and the implications of these for patient involvement and IPC. These insights form a necessary basis for intervening in the complexities of their everyday ways of working.

A unique feature of this VRE study is that nurses were invited to enter into the vulnerable position of being receptive to patient scrutiny of their clinical practices and relationships. We know that when patients question clinicians' IPC practices face to face (e.g., asking clinicians if they have washed their hands), they can meet with resistance or hostility from staff (Davis et al., 2015). By carefully navigating relationships and sensitivities among participants during the research process, we found that nurses remained open to patients' comments and committed to finding solutions to the issues raised (Collier & Wyer, 2016).

Above, we noted how the affective impact of video reflexivity has been attributed to how viewing video simultaneously "distances and presences" taken-for-granted aspects of existence. Rather than confronting participants with bare claims and assertions, this study mediated clinicians' and patients' impressions and responses, using video footage, and relied on this dual effect to broker new relationships between them. This

approach meant that patients felt safe to question practices and share their insights through a third party (facilitator/video) and clinicians could hear patients' messages without feeling directly confronted in a busy clinical environment.

In this study, the researcher was also open to uncertainty and vulnerability by allowing herself to affect and be affected by the research environment (see Collier & Wyer, 2016). This was required so as to become sensitized to what mattered most to the participants (Iedema & Carroll, 2015). Pink (2007) has described the advantage of video as producing empathetic engagements that can enhance the researcher's understanding of another's experience with an eye to better representation. With VRE, this advantage is recognized and extended in that creating and reviewing video footage *together* served to establish "trusting entanglements" (Carroll et al., 2008) between all parties that enabled the potential for learning and change. Here, the reflexive skills and sensitivities of the researcher are crucial for creating and maintaining research relationships that inspire sufficient trust and confidence for participants to risk collaborative scrutiny of work practices and relationships (Collier & Wyer, 2016; Iedema & Carroll, 2015).

In all, it was the careful assemblage of the VRE methods, the involvement of nurses, patients, *and* researchers as coparticipants throughout the process, and the careful facilitation by the researcher in managing the affective potential at every stage that created the affective space in which new possibilities for interaction could be realized. This assemblage also assisted in creating what Edmondson (2008, p. 257) describes as the "conditions of psychological safety," which she argues are essential for productive team learning.

Finally, this VRE study harnessed patients' experiences not just to elicit an emotional response but to generate an affective environment where clinicians were invited to relate to patients and one another. This environment led them to reconsider how they relate to and communicate with their patients and how they will enact IPC and patient involvement in the future. As such, VRE acted as a methodological resource for engaging practitioners, patients, and researchers with the everyday complexities and affective dimensions of IPC. Anchored to affect as a critical dimension of how research unfolds (Iedema & Carroll, 2015), VRE enabled us to consider how we might tackle situations that raise questions about taken-as-given practices, understandings, and expectations. VRE defers conventional role allocations, using neither a precircumscribed data set nor strictly proceduralized analytical methods and taking local complexity and future action as points of departure. As such, VRE moves beyond "a narrow scientism where qualitative research is reduced to an instrumentalism," "toward inventing practices that do not yet exist" (Lather, 2014, p. 8).

Conclusion

In this study, to expand what we know (and can do) about patient involvement, VRE was deployed as the means to intervene in existing relationships and practices. Capitalizing on, rather than dissimulating, its own effect on sites of practice,

VRE researchers harness the camera as flexible technology and use the visual medium as an affect-rich resource for involving and “moving” participants. In these ways, we operate outside of the conventional knowledge-generation paradigm, eschewing “cognitivist” assumptions that information about our circumstances and activities is sufficient for acting on or intervening in them (Still & Costall, 1991). Indeed, VRE’s post-qualitative stance is most evident from its pragmatist insistence that researchers become embroiled with in situ activities, relationships, and tensions (Iedema & Carroll, 2015). It does so not principally to represent “what is” as knowledge but to recount what happened and what changed as a result of such research affecting what is (Rosiek, 2013).

As we have shown in this study, it is this reflexive, collaborative, and interventionist orientation of VRE that stimulates stakeholders’ awareness of and practical responses to complex and unexplored issues, such as “what are we supposed to be doing for patient involvement in IPC?” “what are we doing currently?” “why are we practicing on the basis of different assumptions and interpretations?” and “what is possible and necessary now to optimize IPC and patient involvement?” Its post-qualitative orientation predisposes VRE to engage with and play off against one another, participants’ views, concerns, positionings, and relationships. Here, “what is” is not principally regarded as an object for researchers to analyze but is approached as a dynamic process that still harbors the potential for clinicians and patients to reconsider and reshape how they enact and experience care.

Author’s Note

A separate but related article, detailing Phases I and II of this study, is available at doi:10.1111/jocn.12779.

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7.2 Conclusion

This chapter provided an account of a new application of VRE. Presenting nurses with footage of *in situ* clinical care interactions, in conjunction with patient analyses of this care, facilitated a shrinking, not only of a the research/practice gap but also of the patient/clinician feedback loop. This application of VRE created an affective space that assisted the nurses to confront and begin to come to terms with the practical and relational dimensions of IPC and patient involvement in IPC.

Chapter Eight Conclusion

8.1 Introduction

In Chapter 3, I stated my two main aims for this study. The first was to invite patients to become more active participants in HAI prevention so that together we could examine, *in situ*, whether and how they negotiate and enact IPC. The second aim was to extend the use of VRE in two ways: first, by inviting patients to scrutinize videoed care interactions to see whether this reflexive process could heighten their awareness of transmission risks and safety practices, and motivate them to find better ways to have their IPC needs met³⁴; second, to explore whether feeding-back patient insights, to clinicians who care for them, might broaden clinicians' understandings of infection risk and assist them to appreciate the potential for greater patient involvement. VRE is a collaborative and participatory methodology and I wanted to ensure that patients (and clinicians) would be involved in ways determined by – and negotiated with – them, in order to avoid privileging my role as a researcher. For instance, not all patients wanted to be involved in videoing. The insights of these patients (prominent in Chapter 5) were obtained largely through my spending extended periods with them, on the ward and in other parts of the hospital, as well as engaging in unstructured, conversational interviews with them.

My empirical chapters are all published papers that include conclusions and recommendations. To avoid excessive repetition, in this final chapter, I summarise the key findings as they relate to each of my research questions and articulate the unique contributions of my research to extending the empirical literature on patient involvement in HAI and IPC research, as well as the methodological scope of VRE. I set out the strengths,

³⁴ As had been the case for clinicians involved in similar VRE research.

limitations and some of the salient challenges of the study and make recommendations for future courses of action in clinical and research arenas.

8.2 Addressing the Research Questions

Research Question 1: How do patients understand, negotiate and enact safe or unsafe IPC practices?

There is a dearth of published research that explores IPC with patients, while care is actually happening for them and around them in all its complexity. This thesis contributes to redressing this gap. Rather than using methods that draw on clinician or researcher viewpoints of what patients might do to ensure safety, my aim was to explore how patients *themselves* define infection risks and the activities they engage in, based on these perceived risks: an *exnovation* of patients' existing resources for enacting safety. This research question is addressed in Chapters 5 and 6.

The patients involved in this research were not passive observers of IPC. Many were already actively trying to negotiate safety with clinicians or taking steps to keep themselves and others safe, but faced barriers when trying to engage with staff. For example, patients wanted to understand more about transmission risk and IPC practices. Unfortunately, they *all* had trouble obtaining information even when actively seeking it. Many stated they had never received any guidance or instruction about IPC; some had been given written information but did not find it useful; and some had been given partial or contradictory information. As a result they had poor understandings about HAI and transmission risks and limited understandings of how to keep themselves or others safe from infection. This has been a consistent finding in the literature for the last three decades (Guilley-Lerondeau et al., 2017; Mutsonziwa & Green, 2011). This lack of engagement could be “harmful in and of itself” (Collier et al., 2016, p. 70) as patients were afraid to ask questions or to speak up when they witnessed staff practicing what they perceived to be substandard infection control. They

feared offending their healthcare professionals and the possible repercussions this might have on their care (Ahmad et al., 2016; Dancer, 2012; MacDonald, 2008; Seale, Travaglia, et al., 2015).

In the absence of guidance from their healthcare providers, I observed many patients engaging in risky behaviours that could potentially contribute to patient-to-patient transmission of MROs for example, patients sitting on other patients' beds and sharing personal items, or relatives taking home washing for non-related patients. Almost all source-isolated patients left their rooms regularly to use communal areas of the ward and hospital, or to visit other patients. Many of these patients did not take appropriate transmission precautions and were potentially contributing to environmental contamination and transmission of MROs (Banfield & Kerr, 2005; Cao, Min, Lansing, Foxman, & Mody, 2016; Istenes et al., 2013; Sunkesula, Kundrapu, Knighton, Cadnum, & Donskey, 2017).

At the same time, to compensate for the lack of engagement and information from their healthcare professionals, the patients in this study sought other ways to learn more about HAI and IPC. Contrary to other research (Burnett et al., 2010; Gleeson et al., 2016), very few patients in this study accessed the Internet or other media for information. Some sought information from other patients and relatives on the ward. However, the most common way that patients learned about IPC was through observing their healthcare professionals. Other studies have reported on how patients monitor clinicians' activities around IPC, and, from this, form judgments about good practice and the quality of the care they receive (Barratt et al., 2010; Skyman, Sjostrom, & Hellstrom, 2010). My study linked patients' observations and judgments of practices not only to their understandings of IPC (or lack thereof), but also to how this influenced their own infection control behaviour and its potential impact on infection transmission. My research found that clinicians' inconsistent practices and a lack of

engagement with patients around IPC resulted in patients developing sometimes skewed or erroneous notions of transmission prevention. From this foundation, they developed a range of strategies, of variable effectiveness, to reduce transmission risk.

The findings of this study, therefore, contribute to emerging research in the broader patient safety field by showing that patients are actively engaged in producing safe and unsafe IPC practices and that clinicians and researchers would do well to engage with these activities if they wish to reduce HAI (Collier, 2013; Hor et al., 2013). Furthermore, this research has shown that effective reduction of infection transmission relies on *ongoing* patient-clinician collaborations (Collier et al., 2016). Many patients in this study positioned themselves as members of the IPC team, but found little value in receiving leaflets or one-off education sessions (or no instruction at all) to prepare them for this role. What they desired was ongoing dialogue with their clinicians that would provide details and updates on their diagnosis and treatment, as well as incremental explanations and guidance on how they could enact effective IPC.

Research Question 2: Can VRE support patients to better understand IPC practices, and how their IPC needs might be better met?

As discussed in Chapter 2, a large proportion of studies that involve patients in HAI and IPC research have been conducted through quantitative survey and the use of standardised-measurement tools or qualitative interviews that rely on participants' memories and espoused opinions. In Chapters 3 and 7, I argue that this fails to address the gap between what people *say* they know, do and practice, and what they enact or experience *in situ* (Greatbatch et al., 2001). The limitations of these research methods become even more pronounced when considering the number of studies in which data were collected many months after patients had left hospital. In one study of experiences of source-isolation, interviews were conducted up to three years after discharge (Skyman et al., 2010). Thus, we do not gain insight into the

way in which infection control is experienced, shaped into understandings, tested out, adapted or adjusted, re-ascribed meaning, and so on, by patients in their complex moment-to-moment and day-to-day interactions and experiences in hospital. This VRE study, as far as I am aware, is the first to conduct research alongside and with patients, by viewing videoed care practices to identify safety risks. This approach provided a powerful way of bringing the here-and-now into focus for patients, foregrounding their experiences in real-time complexity, and stimulating discussion that has led to new ways of understanding and enacting IPC.

Just as clinicians have been enabled to apprehend a different view of their practice, by viewing and discussing video footage of clinical practice (Carroll, 2009a; Forsyth, 2009; Hor et al., 2014; Iedema et al., 2015; Iedema, Merrick, Rajbhandari, Gardo, & Herkes, 2009; Iedema, Mesman, et al., 2013), the patients in this study also came to see clinical practices and their relationships with healthcare professionals in a new light. Chapter 6 showed how patients involved in VRE were able to identify previously unrecognised infection risks in their environments and interactions and, through reflexive discussions, came to new understandings about how safe or unsafe some IPC practices are. For example, most patients gained new understandings about glove use and its relation to hand hygiene. They also became more aware of their habituated patterns of behaviour, particularly the roles they had internalised in their interactions with their healthcare professionals and how this affected their abilities to have their own infection control needs met.

Put differently, patients were able to identify disconnects between how they experience, understand and enact infection and how they *would like to* experience, understand and enact infection control (Iedema, 2011b). This had a transformative impact, affecting them in such a way as to develop a heightened awareness of how their actions might impact upon safety,

motivating them to develop new strategies for relating to healthcare professionals and contributing more effectively to the safety of themselves and others.

Research Question 3: Can VRE strengthen clinicians' awareness of and commitment to patient/clinician relationships that support patient involvement in IPC?

The answers to Research Question 1, while important and enlightening, would remain in the knowledge paradigm if this research only took them as far as being published in the journal articles presented in this thesis, for any interested clinician, patient or academic, who might be sufficiently affected by them, to act on the findings. Furthermore, while individual patients benefited from the learning afforded by video-reflexivity (as shown in the discussion above answering Research Question 2), their newfound insights about infection risks and healthcare relationships might also have only been represented, in written form, in the paper found in Chapter 6. I sought to close not only the research-practice gap but also the feedback-loop between patients and clinicians. By presenting nurses with footage of real-time care practices in conjunction with their patients' feedback on this care, I hoped to provide an opportunity for them to directly comprehend and be affected by their 'entanglements' with patients. Chapter 7 established that this novel use of VRE can enable clinicians to: 1) better understand how their own views about what constitutes good IPC practices and relationships might align with the views of patients under their care; 2) to see how mismatches between the two can impact upon patient safety issues like HAI; and 3) to reflect on what could be done differently.

For the nurses who participated in this part of the study, comprehending care from patients' perspectives brought to light several potential benefits as well as practical issues that hinder patient involvement in IPC. The nurses were surprised to find that some patients were far from passive recipients of IPC and were able to recognise and discuss multifaceted infection risks, some of which the nurses themselves had not imagined, or had taken for granted in

their busy work environments. For example, what types of gloves³⁵ should be worn and when; or how a patient might transmit pathogens after an infected limb has been removed³⁶. Contrary to their previous assumptions, the nurses realised that patients in their care were not receiving adequate information about HAI and IPC from any of their healthcare professionals. The nurses learned that, to compensate for this lack, patients were observing care closely and basing their understanding and behaviours on clinicians' (sometimes) inconsistent practices. This led the nurses to understand that some of the patients' behaviours around IPC, which the nurses had until that time considered acts of disregard or non-cooperation, were in fact a result of poor nurse/patient communication as well as nurses' own confusions about IPC practice.

This new application of VRE also generated safe spaces in which groups of nurses could develop their affective intelligence (Iedema, Mesman, et al., 2013), namely the ability to collaboratively develop responses to the relational and affective dimensions of patient involvement. In the VRE literature it has been discussed how the 'distancing and presencing' effect of video feedback can bring into present focus what "has thus far remained in the background", while at the same time unhinging or 'distancing' viewers from their practices just enough so that they can question "the assumed inevitability of practices, and [...] the structures of feeling that define them" (Carroll et al., 2008, p. 388). In this study, my use of video feedback also had the dual effect of mediating patients' insights such that the nurses were affected, but not antagonised, by patients' views. Given this space, the nurses were able to grasp the challenges that patients faced, trying to access information and keep themselves and others safe. The process also brought into focus the problems nurses themselves

³⁵ For example: sterile or unsterile/clean gloves.

³⁶ This relates to the difference between colonisation and infection mentioned in Chapter 7. When an infected limb was covered by a dressing, or had been removed, many patients and even some staff were confused about why a patient would still be infectious.

experienced in initiating difficult conversations about HAI and negotiating IPC practices with patients and visitors. This led them to reconsider how they relate to and communicate with their patients, *and* each other, and to develop strategies to promote greater patient involvement. In particular, they decided that they should engage in more everyday, ongoing conversations with patients about IPC, rather than relying purely on formal education by infection control practitioners – no matter how difficult these conversations might be.

Finally, VRE provided space and time for the nurses to become mutually attuned to the implications of team members' varying positions on patient involvement and IPC practices in general. Although these variations were not always resolved by consensus, the nurses came to a greater understanding of their own and others' practices and viewpoints, opening up opportunities for evaluating and adjusting these variations where appropriate.

In summary, the novel use of VRE in this study provided a vehicle for examining nurse-patient relationships and IPC practices, *in situ*, from patients' perspectives. This enabled the nurses to realise: 1) that patients were actively contributing to IPC in ways that nurses were not fully aware of; 2) that the quality of patient/clinician relationships and IPC conversations (or lack thereof) shaped these contributions, leading to behaviours that were variable in effectiveness; and 3) that by engaging with their patients' contributions more closely, they could work together to reduce infection transmissions on their ward.

8.3 Implications of the Findings

Several implications for clinical practice are included in the articles comprising Chapters 5,6 and 7. First and foremost, if clinicians are serious about reducing HAI, they must consider patients and their visitors as active and equal partners in IPC.

It's like the team is out there playing and one important section of the field is not being included in the game plan. (Katherine Carroll, personal communication, March, 2014)

Patients have the most at stake when it comes to HAI, and this research has shown that many are willing, able and essential members of the IPC 'team'.

While the concept of patient involvement in their care, and how to improve it, has become a key goal for ensuring safety, now mandated in policy and professional documents (ACSQHC, 2011; WHO, 2014), it is still in its infancy. Debates rage around definitions and frameworks for how to involve patients (Domecq et al., 2014; Ives et al., 2013; Staley, 2013). Meanwhile, clinicians are expected to 'empower' and involve people in their care and patients are encouraged to take on new and unfamiliar roles as active participants in the production of safety, with little practical advice for either group on how this can be achieved (Sharp et al., 2014). In most guidelines, patient involvement in IPC is often framed in terms of educating patients about IPC rules, so as to empower them to take an active role (ACSQHC, 2011; WHO, 2009). It is of course important and ethical that patients and visitors receive adequate information about HAI and IPC strategies so that they can make decisions about their care (Sharp et al., 2014), and help to prevent transmission of infection to others. This research demonstrates however that this must be the responsibility of *all* healthcare providers, not just the few ICPs that service the whole hospital. Furthermore, this information needs to be provided to *all* patients, not just those who are infected or colonised with MROs. Patients acting on such knowledge could reduce their chances of MRO acquisition. Patients and visitors should also be more involved in developing content and delivery modes for IPC information for hospital inpatients as well as that used in education for clinicians.

This research has shown, however, that patient involvement requires more than simply educating stakeholders about IPC. Although this is important, even patients who are well informed and empowered take their knowledge and skills into a “messy, idiosyncratic and unpredictable world” (Greenhalgh, Snow, Ryan, Rees, & Salisbury, 2015, p. 1), where the affective and relational aspects of care can act as barriers to communicating and enacting IPC. Hence, ongoing dialogue between patients and clinicians is likely to be more effective than one-off didactic education (Seale et al., 2016). One conversational strategy that clinicians could adopt is to explain IPC practices to patients as they are performing them, whereby clinicians model appropriate and safe behaviours as well as opening up safe spaces for patients to ask questions and to build on their knowledge over their hospital stay. This approach was found to be successful in a recent study by Caine, Pinkham and Noble (2016). They found that when staff informed patients of the rationale for hand hygiene whilst staff were cleaning their own hands, it raised *both* staff and patient awareness of appropriate personal hand hygiene without causing tension or friction between parties.

Critically, my research also demonstrates the value of closing the patient-clinician feedback loop in a way that is close to *in situ* practice, so that it respects and includes the everyday complexity of care delivery. This VRE study offered a safe space for nurses to be able to do this: to step back from the business of their everyday work; to listen to, and be affected by, patients in their care; and to “produce actionable knowledge that is directly applicable to the translation of [patient-centred care] into daily practice” (Liberati et al., 2015, p. 51). Here, the value of employing video footage is that it elicits more from patients than just memories and opinions about previous care experiences. Rather, it allows patients to refer to specific aspects of care practices and relationships that clinicians can then focus on with an eye to practice change. Embedding reflexive and ‘exnovative’ activities like VRE in clinical units would provide an ongoing way for ward staff to engage with patients and explore the

potential for patient involvement in patient safety on their wards. While reflexive skills and sensitivities are crucial to enable effective practice change through VRE, the facilitation of VRE projects need not always be researcher- (or ‘outsider-’) led. This is evidenced by groups of healthcare professionals in the Netherlands and the United Kingdom who have led VRE as a practice improvement method in their hospitals and/or units (Caldwell, 2009; Iedema, Mesman, et al., 2013, pp. 106-151; Mesman, 2016). The success of these endeavours, combined with the findings of this thesis, point to the potential for VRE to be more widely adopted by clinicians, educators and patients, to explore patient involvement as part of ongoing care delivery.

Making time to step outside of the pressures of everyday work to engage in conversations and reflexive work can be considered an unaffordable luxury in the resource and time-poor contexts common to healthcare work. Yet it has been argued that the key underlying principle of reflexive practice is that the “busier we are, the more reflective we need to be” (Thompson & Thompson, 2008, p. 8). Changing thinking on this matter will require deliberate effort at research, healthcare management and health worker levels to consider and promote different ways of understanding safety and to provide time and resources that enable frontline actors to become aware of their existing relationships, activities and habituations (Iedema, Mesman, et al., 2013).

8.4 Strengths, Limitations and Challenges

In this study, my supervisors and research team offered me the incredible opportunity and freedom to explore new ways of using VRE and I undertook this challenge with a beginner’s naïveté. My openness and enthusiasm was certainly of benefit but my lack of experience also resulted in several limitations of the study. My biggest regret is not involving patients in the study planning. To a certain extent this was out of my control in that the research protocol for

the larger project had long been submitted and accepted by chief investigators and ethics committees prior to the commencement of my PhD. Furthermore, ethics committees required that my request for amendment included a clear research plan and consent form before fieldwork began which would have made it difficult to negotiate objectives with patients on the ward. At the time, however, it did not even occur to me to involve patients in the study design. Therefore decision-making at this stage of the research privileged my own research goals. By the time fieldwork commenced, my understanding of participatory research had deepened and I was able to encourage patients to participate directly in research decisions by choosing how they wanted to be involved, making decisions about what would be videoed, scrutinising and analysing footage, deciding what would be shown to clinicians or at conferences, refining themes, co-writing academic publications, and presenting at conferences with me. It is worth noting that, when I presented at conferences specifically focused on patient involvement in IPC, my requests for funding to include a patient participant as a co-researcher and co-presenter could not be accommodated by the conference organisers.

Minimising harm

As Bergold and Thomas (2012) point out, “research project(s) and the publication of the results can have considerable negative consequences for the research participants” (p. 217). During my study, all participants made themselves vulnerable to scrutiny of their practices and relationships, in order to capitalize on the learning this could afford. In Chapter 4, I explain how I enacted researcher reflexivity in the field to minimise harm to participants. Since then, I have continued to maintain open and honest communications with patients who were involved in this study. I send regular updates about the research to all interested participants, and continue to ask for their consent when presenting outcomes from this research. For instance, Chapter 7 features video footage and photographs of two patient co-

researchers, while another section of footage from this study was used in a NSW Health online mandatory training program (Health Education and Training Institute, 2015, July 06). Although I had secured media releases from those featured, giving me permission to use the footage in academic publications and for educational purposes (see Appendix F), I also contacted these people to describe how their footage would be used and to seek their permissions again. In particular I was mindful of Bergold and Thomas' warning:

Neither the researchers nor the research funders can exercise sufficient control over the way findings are reported. Therefore, it is always necessary to reflect with the affected persons about what can happen when hitherto invisible, taboo problems are made public (p.217).

I therefore negotiated with patient co-researchers which footage or pictures would be used (if any) and whether they wanted their faces blurred. These patients decided that the need for a better understanding of the challenges faced by patients around HAI trumped their desire for anonymity. However, risks and harms remain possible as a result of this research, as they do in healthcare research generally.

Limited Engagement

Finally, I did not set any rigid inclusion or exclusion criteria for participation in this research and I was open to finding ways for any patient or visitor to be included. I believe I did my best to engage with patients and relatives from many different circumstances and backgrounds. If patients were unconscious, disoriented or confused, I spoke to their relatives, instead, about being part of the research. Several participants with developmental or physical disabilities became involved and shared their unique perspectives. Despite the offer of an interpreter, my efforts to engage patients and relatives who spoke little English, and who therefore may have faced different challenges (particularly around access to information),

were mostly unsuccessful. Only one patient who did not speak English agreed to an interview with an interpreter and none was involved in video-reflexive activity. Similarly, only two relatives were involved in the study, both consenting to interviews only.

Many of the nurses in the ward were actively involved in the larger project. Perhaps because of my background and familiarity with nursing, the logistical convenience of arranging reflexive sessions with one clinical discipline, and the desire to keep my PhD manageable, nurses were the only group of clinicians with whom I conducted reflexive sessions³⁷. In hindsight, I wish I had strived for more multidisciplinary reflexive sessions. This would have provided wider audiences for patients' voices to be heard and would also have provided the opportunity for interdisciplinary negotiations of patient involvement in IPC. I did, however, seize opportunities to present at meetings held by other disciplines, for example, doctors' grand rounds and multidisciplinary leadership committees.

More than half of the nurses from this ward attended reflexive sessions, however, nurse managers did not attend, despite repeated invitation. This may have precluded richer discussion and actioning of resolutions. Then again, I suggest that it is not only the solutions themselves that will advance patient involvement (Iedema et al., 2015). In the fast-paced and changeable surgical ward environment some of these solutions might not see the light of day, some might become irrelevant and others might endure but need updating and revising. Rather, it is the development of the nurses' collective and affective capabilities to hear, discuss and question their own responses to patient analyses of the care they receive that can orientate nurses to better understandings of what patients need, and prepare the way for more open dialogue with patients.

³⁷ I did video one interaction between a patient and a doctor. However, an appropriate opportunity to engage in a reflexive session using this footage did not eventuate.

8.5 Future research

This thesis gives rise to a number of considerations for future research into patient involvement in patient safety. The first is that researchers must become more open to new paradigms of health service research if our aim is to confront and tackle intractable healthcare problems. This thesis has argued that the methods used in positivist and conventional social science paradigms are too distanced and objectifying to address the complexity of social and organisational problems in healthcare. Yet, these remain the dominant healthcare research paradigms. Communities of researchers maintain the disciplinary boundaries of their paradigms and methods in pursuit of quality and rigour (Cheshire, 2016, July) and, some argue, in pursuit of authority and material resources (Gieryn, 1983). Others suggest that, when addressing healthcare safety, perhaps it has been easier to research where we are comfortable – at a distance, using objectified data – than to engage with the complexity and unpredictability that frontline actors face (Iedema, Mesman, et al., 2013). However, the growing complexity of peoples' illnesses and healthcare services means that we can no longer ignore or distance ourselves from this frontline complexity.

Recently, some researchers have turned toward 'post-qualitative' or 'post-humanist' research, which invites researchers to think outside of prevailing methodologies that aim to uncover truths about human behaviour (Lather, 2013; St. Pierre, 2014). Post-qualitative researchers argue for theoretically informed research that can spark new types of analytical practices, researcher subjectivities and theories of change (Lather, 2013). The ontological and epistemological foundations of VRE, the theories that drive its pedagogic endeavours, and its eschewal of strict methodological *a priori* decision-making, orient it as a post-qualitative approach. This thesis has shown that VRE can rally patients, clinicians, researchers and other stakeholders to explore new ways of observing, thinking and talking about wicked problems

such as HAI, and can enable them to find new ways of seeing, being and acting together to create safer care.

As such, further research aiming to involve patients in HAI research should consider video-reflexive methods. The value for researchers embracing VRE is its narrowing of the research/practice gap and the patient/clinician feedback loop. Video offers real time data, which can be understood by everyone, to some extent, at face-value, and can short-circuit peoples' understandings about how care works and their roles in it. Investigations of patient involvement using VRE as outlined in this thesis could also be used in other care settings and across all spheres of healthcare.

I would also recommend that patients and clinicians become more involved in the early stages of VRE research projects. Their insights into relevant safety issues and how to best involve patients is vital to ethical and effective research. Other ways of scrutinising and analysing video footage with patients could be explored. During this research, on several occasions, I organised and facilitated reflexive sessions where the patient, the nurse and I viewed footage together. The resulting discussions showed promise but were not frequent enough or explored in enough depth to include in this thesis. I have also considered the potential of facilitating reflexive session with groups of patients to provide opportunities for them to draw on *their* shared intelligence and increase their potential for adaptive practice. Even more beneficial could be the careful facilitation of reflexive feedback sessions involving both patients and members of the multidisciplinary clinical team.

In short, research in this post-qualitative, post-humanist paradigm, as championed in this thesis, is not about merely trying to make sense of healthcare and safety, but about changing it, together, in the here-and-now. Given the complexity of contemporary health care practices, our understanding of such practices will always and necessarily lag behind what is going on,

and be out of sync with what frontline staff and patients need to know, agree to, and do to manage care safely. I recommend that future research in patient involvement in IPC, and patient safety in general, should not focus solely on influencing what people do through standardised rules or imposing predefined interventions, but must also ensure that people are given the opportunity to learn about and reflect together on the complex practical, affective and relational aspects of their work.

8.6 Conclusion

This thesis explored new ways of researching with patients and clinicians amidst the *in situ* complexity of everyday IPC practices and interactions. By engaging with this complexity and offering patients opportunities for greater decision-making throughout the research, I found that patients' roles for ensuring safe care and reducing infection transmission had been underestimated. The patients in this study had varying degrees of IPC knowledge and expertise that they had formed largely in the absence of input from the clinicians who cared for them. From these, often patchy, understandings, they had developed ways to keep themselves, and others, safe from infection. Clinicians were generally unaware of patients' IPC activities and were therefore not supporting effective patient strategies, nor intervening to rectify counterproductive strategies. In the words of one patient, "Nobody seems to talk about it." This is not to suggest that the lack of engagement was due to a lack of care on the part of clinicians. The nurses who took part in the study were respectful, professional and interested in finding ways to engage more with patients. They were also deeply concerned with the high levels of MRO transmission on their wards and dedicated to finding ways to reduce HAI. Rather it points to a recurring theme in the talk of both patients and nurses - that HAI and IPC are difficult subjects to talk about. This study provided a safe space for everyone involved, to negotiate these difficulties and reflect on and reshape their assumptions, roles and practices.

Two main conclusions emerge from this research. First, that patient involvement is an interpersonal, affective dynamic, the quality of which can strongly influence IPC behaviours. Second, that video footage can provide an important springboard for revealing and grappling with this affective dynamic. Reflexive viewing of video footage connected everyone involved to the practical and affective complexities of everyday moment-to-moment care, and enabled them to develop strategies for safer work practices and relationships. Patients were able to develop more critical understandings of infection risks and of how to have their IPC needs better met. Confronted with footage of everyday practice, alongside patients' observations on the same practice, nurses were obliged to recognise the expertise of patients and to acknowledge that patients, visitors and staff are 'entangled' in relationships and activities that impact on how safe or unsafe IPC unfolds. This assisted the nurses to understand that the quality of their relationships and IPC conversations with patients were critical to safer care.

8.7 Final Thoughts

The patient co-researchers in this study, particularly those who remained in contact and/or have worked closely with me over the last five years, have influenced how I will conduct research for the rest of my career as well as the way I approach my clinical nursing work. They have taught me how to conduct respectful and ethical research and have inspired me to have regular, ongoing IPC conversations with patients I have cared for since starting this research, as well as those I will care for in the future. I believe that some of these people have been affected by their involvement in this research too. Some of them have presented at conferences with me and have written (or are currently writing) journal articles with me. One is now a patient consultant on three different hospital advisory committees. Footage from this research, describing one of my co-researcher's experiences of HAI, also features in an online mandatory training module for NSW Health. Others tell me they now speak up when they observe lapses in IPC practices or need more information when making choices about care.

The effect of the strength of our relationships and shared understandings has made us ‘more’ than we were before.

I would like to end this thesis by sharing this email, written by one of my patient co-researchers after I requested permission to use some of his photos and footage in a presentation. His expression that the message of this research is a co-constructed effort – a message ‘we’ are trying to get across - was particularly heartening for me, and is at the core of this thesis.

Hi Mary

Thanks so much for sending the video and photos. I feel that [...] removing this video and photos would hinder the message that we [are] trying to get across.

Please feel free to use them, as I believe it will get the message across where it is needed and I am always more than glad to help you with your work and wish I could do more.

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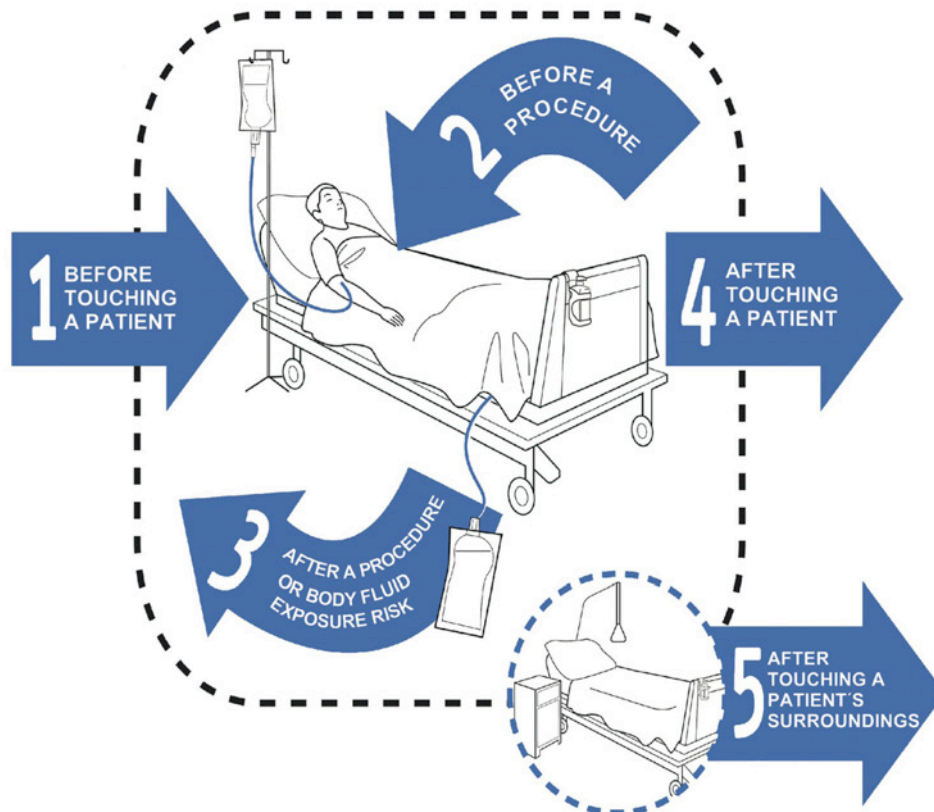
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Appendix A: 5 Moments of Hand Hygiene Poster

5 Moments for HAND HYGIENE



1 BEFORE TOUCHING A PATIENT	<p>When: Clean your hands before touching a patient and their immediate surroundings.</p> <p>Why: To protect the patient against acquiring harmful germs from the hands of the HCW.</p>
2 BEFORE A PROCEDURE	<p>When: Clean your hands immediately before a procedure.</p> <p>Why: To protect the patient from harmful germs (including their own) from entering their body during a procedure.</p>
3 AFTER A PROCEDURE OR BODY FLUID EXPOSURE RISK	<p>When: Clean your hands immediately after a procedure or body fluid exposure risk.</p> <p>Why: To protect the HCW and the healthcare surroundings from harmful patient germs.</p>
4 AFTER TOUCHING A PATIENT	<p>When: Clean your hands after touching a patient and their immediate surroundings.</p> <p>Why: To protect the HCW and the healthcare surroundings from harmful patient germs.</p>
5 AFTER TOUCHING A PATIENT'S SURROUNDINGS	<p>When: Clean your hands after touching any objects in a patient's surroundings when the patient has not been touched.</p> <p>Why: To protect the HCW and the healthcare surroundings from harmful patient germs.</p>

Appendix B: Literature Pertaining to Patient Involvement in HAI and IPC research and initiatives

Providing Feedback

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Interventions at point of care

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Participatory research

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Appendix C: Participant Information Handout



“Strengthening frontline clinicians’ infection control: A multi-method study to reduce MRSA infection and transmission”

Aims

This NHMRC-funded project based in [REDACTED] hospitals aims to reduce the rate of hospital-acquired infections by providing staff with rapid feedback about MRSA transmissions, as well as video feedback around work practices.

Methods

Two researchers, Su-yin Hor and Mary Wyer from the University of Technology, Sydney (UTS), will be carrying out the research in [REDACTED]. This will involve:

1. Interviewing and consulting staff about infection control – and their experiences of dealing with infection in this ward. Researchers will work with staff to identify particular issues or practices to focus on.
2. The researchers, working with staff guidance, will ask for permission and video-record practices that staff would like to look at.
3. The researchers will edit the footage, and with the permission of those videoed, show it back to staff in *reflexive feedback sessions*. The aims of these sessions are for staff to reflect collaboratively on their work in a supportive environment, and to discuss what they can do to further prevent the spread of infection in the units.
4. These video feedback sessions will happen every 2-3 weeks, depending on availability and need. The project will continue for approximately 3 months (March to May 2013) with the aim to repeat this process in 2014.
5. We will also invite patients and carers to participate in the project, focusing on their experiences, informational needs, and communication with staff. With their consent, video footage created with patients may also be shown back to staff, to provide feedback about the experiences and needs of patients with MRSA, and the roles they may play in infection control and prevention.

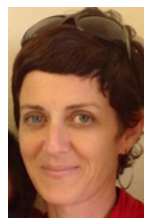
Ethics

Formal ethics approvals for this project have been obtained from the Human Research Ethics Committees of the WSLHD and UTS. Clinicians (and patients) are invited to participate on a **voluntary** basis, and any video recording will depend on formal consents obtained ahead of time, as well as ongoing verbal consents at the time of the recordings.

Researcher details



Su-yin Hor
Senior Researcher
BPsych(Hons), MEd, PhD
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Mary Wyer
PhD Student
BA(Hons), DipEd, RN
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9514 3895 (office)

Appendix D: Clinician Information Sheet and Consent Form

PARTICIPANT INFORMATION SHEET AND CONSENT FORM **Clinician**

Study Title: **Strengthening frontline clinicians' infection control: A multi-method study to reduce MRSA infection and transmission**

Chief Investigator: Professor Rick Iedema
Centre for Health Communication, University of Technology, Sydney

Invitation

You are invited to participate in a research study into how clinicians can limit cross-infection risk.

The study is being conducted by Professor Rick Iedema (University of Technology Sydney), Professor Lyn Gilbert (Centre for Infectious Diseases and Microbiology), Dr Claire Hooker (Centre for Ethics, Values and the Law in Medicine), Dr Matthew O'Sullivan (Centre for Infectious Diseases and Microbiology), Associate Professor Christine Jorm (University of Sydney, Office of Medical Education), Dr Su-yin Hor (University of Technology Sydney) and Ms Mary Wyer (University of Technology Sydney).

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

What is the purpose of the study?

The purpose is to investigate whether we can improve clinicians' ability to avoid patients getting infected. We will do so by providing quick turn-around information about existing infections, infection spread, filmed evidence of clinical work practices in domains where there is infection spread, and reflective meeting to enable clinicians themselves to understand the risks, and devise strategies for limiting those risks.

Who will be invited to enter the study?

You are invited to participate in this study because you are a clinician working in one of the participating units.

Do you have a choice?

Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect your employment with the Western Sydney Local Health District. If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason.

There will be no consequences for you if you decide to withdraw from the study.

What will happen on the study?

If you agree to participate in this study, you will be asked to sign the Participant Consent Form. This study will be conducted over 3 years.

The work practices that are studied are those that carry risk of cross-infection. Clinicians may reflect on these practices and decide to change them with the aim of making them safer; that is, less likely to cross-infect patients. The method deployed for this study is 'video reflexive ethnography'.

PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Clinician

Study Title: Strengthening frontline clinicians' infection control: A multi-method study to reduce MRSA infection and transmission

Video reflexive ethnography involves clinical practices being filmed, and clinicians in the films reflecting on their practices by observing themselves and each other. Research experience has shown that this is a powerful learning tool for practitioners.

If you agree to participate in this study, you may be asked to participate in an interview or interviews, and you may be videoed as you carry out your clinical work. You may also be invited to participate in video-recorded reflexive sessions.

What happens to the data after it has been gathered?

The data is stored and handled at the University of Technology, Sydney, in locked cabinets and on password protected computers, housed in secure offices located in a CCTV-protected special-security space

As the study progresses, the researcher may contact you to ask you for permission to use these data for the reflexive sessions or other educational purposes. The researcher may also contact you to share the results and findings of the study. If you are willing to be contacted for these purposes, please indicate so, and provide an email address and/or phone number below:

I **agree / do not agree** (please circle) to being contacted by the researcher about this study in the future.

Preferred contact email address:

Preferred contact phone number:

Are there any risks?

There may be risks associated with this study that are presently unknown or unforeseeable. In spite of all reasonable precautions, you might experience inconvenience or anxiety from participating in this study. Some people feel uncomfortable being involved in studies that involve interviewing. You may also feel uncomfortable being involved in filming, even if you will not be directly targeted by the camera.

Are there any benefits?

This study aims to further knowledge and may improve future clinical practice in its aim to eradicate cross-infection of patients in hospitals. We cannot guarantee or promise that you will personally receive any benefits from this project, however previous participants in research of this kind have found it beneficial and have experienced a positive impact.

PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Clinician

Study Title: Strengthening frontline clinicians' infection control: A multi-method study to reduce MRSA infection and transmission

Confidentiality / Privacy

The study information will remain confidential and will be disclosed to others only with your permission, or except as required by law. Only the researchers named above will have access to the data gathered and the results. Everything will be held securely at the University of Technology Sydney, and at the Centre for Infectious Disease and Microbiology.

Compensation

If you suffer any injuries or complications as a result of this study, you should contact the study leader as soon as possible, who will assist you in arranging appropriate medical treatment. You may have a right to take legal action to obtain compensation for any injuries or complications resulting from the study. Compensation may be available if your injury or complication is sufficiently serious and is caused by unsafe drugs or equipment, or by the negligence of one of the parties involved in the study (for example, the researcher, the hospital, or the treating doctor). If you receive compensation that includes an amount for medical expenses, you will be required to pay for your medical treatment from those compensation monies. You do not give up any legal rights to compensation by participating in this study.

If you are not eligible for compensation for your injury or complication under the law, but are eligible for Medicare, then you can receive any medical treatment required for your injury or complication free of charge as a public patient in any Australian public hospital.

Will taking part in this study cost me anything, and will I be paid?

Participation in this study will not cost you anything. You will not be paid for your participation in this study.

What will happen at the conclusion of the study?

If the study is able to devise practices or approaches that lead to superior infection control, these will be publicized to other units and organizations, and to national and international policy bodies.

What happens with the results?

We plan to present and publish the results in peer-reviewed journals and at educational and professional conferences, nationally and internationally. In any publication or presentation, information will be provided in such a way that you cannot be identified, unless you give us permission to do so. Results of the study will be provided to you, if you wish.

PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Clinician

Study Title: Strengthening frontline clinicians' infection control: A multi-method study to reduce MRSA infection and transmission
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Complaints

This study has been approved by Western Sydney Local Health District Human Research Ethics Committee. If you have any concerns about the conduct of the study, or your rights as a study participant, you may contact [REDACTED] or email: researchoffice@swahs.health.nsw.gov.au, and quote [INSERT SSA REFERENCE NUMBER].

Contact details

When you have read this information, the researchers Su-yin Hor and/or Mary Wyer will discuss it with you and any queries you may have. If you would like to know more at any stage, please do not hesitate to contact Su-yin at Suyin.Hor@uts.edu.au, mobile: [REDACTED] or Mary at Mary.T.Wyer@student.uts.edu.au, mobile: [REDACTED]. If you have any problems while on the study, you can also contact Professor Rick Iedema, email: r.iedema@uts.edu.au, mobile: [REDACTED].

Thank you for taking the time to consider this study.

**If you wish to take part in it, please sign the attached consent form.
A copy of this information sheet will be given to you to keep.**

PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Clinician

Study Title: Strengthening frontline clinicians' infection control: A multi-method study to reduce MRSA infection and transmission

CONSENT TO PARTICIPATE IN RESEARCH

Chief Investigator: Rick Iedema, University of Technology, Sydney

1. I understand that the researcher will conduct this study in a manner conforming to ethical and scientific principles set out by the National Health and Medical Research Council of Australia and the Good Clinical Research Practice Guidelines of the Therapeutic Goods Administration.
2. I acknowledge that I have read, or have had read to me the Participant Information Sheet relating to this study. I acknowledge that I understand the Participant Information Sheet. I acknowledge that the general purposes, methods, demands and possible risks and inconveniences which may occur to me during the study have been explained to me by _____ ("the researcher") and I, being over the age of 16 acknowledge that I understand the general purposes, methods, demands and possible risks and inconveniences which may occur during the study.
3. I acknowledge that I have been given time to consider the information and to seek other advice.
4. I acknowledge that refusal to take part in this study will not affect my employment with Western Sydney Local Health District.
5. I acknowledge that I am volunteering to take part in this study and I may withdraw at any time.
6. I acknowledge that this research has been approved by the Western Sydney Local Health District Human Research Ethics Committee.
7. I acknowledge that I have received a copy of this form and the Participant Information Sheet, which I have signed.

Name of participant _____ Date of Birth _____

Signature of participant _____ Date: _____

Signature of researcher _____ Date: _____

Signature of witness _____ Date: _____

Appendix E: Patient Information Sheet and Consent Form

PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Patient or Visitor

Study Title: Strengthening frontline clinicians' infection control: A multi-method study to reduce MRSA infection and transmission

Chief Investigator: Professor Rick Iedema
Centre for Health Communication, University of Technology, Sydney

Invitation

You are invited to participate in a research study into limiting cross-infection risk.

The study is being conducted by Professor Rick Iedema (University of Technology Sydney), Professor Lyn Gilbert (Centre for Infectious Diseases and Microbiology), Dr Claire Hooker (Centre for Ethics, Values and the Law in Medicine), Dr Matthew O'Sullivan (Centre for Infectious Diseases and Microbiology), Associate Professor Christine Jorm (University of Sydney, Office of Medical Education), Dr. Su-yin Hor (University of Technology Sydney) and Ms Mary Wyer (University of Technology Sydney).

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

What is the purpose of the study?

The purpose is to investigate whether we can improve clinicians' ability to avoid patients getting infections. We are also interested in the experience and information needs of patients regarding infections.

Who will be invited to enter the study?

Patients and their carers. You are invited to participate in this study because you are a patient being treated by clinicians working in one of the participating units and we believe that patients and their families have valuable insights on how to improve care.

Do you have a choice?

Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect the treatment you receive now or in the future. Whatever your decision, it will not affect your relationship with the staff caring for you. If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason.

There will be no consequences for you or your care if you decide to withdraw from the study.

What will happen on the study?

If you agree to participate in this study, you will be asked to sign the Participant Consent Form.

The method used in this study is 'video reflexive ethnography'. Video reflexive ethnography involves everyday practices being videoed, and the people in the videos reflecting on their practices by observing themselves and each other in the footage. Research experience has shown that this is a powerful learning tool for participants..

If you agree to participate in this research there will be various options that you can choose from. If necessary, an interpreter will be employed for interviews with participants from non-English speaking backgrounds. Please select one or more of these options:

Master version for multi centre (Patients and Visitors)
Version No 5 Dated 5/2/2013

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PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Patient or Visitor

Study Title: Strengthening frontline clinicians' infection control: A multi-method study to reduce MRSA infection and transmission

☐ **Option 1: Interview(s)**

Participate in one or more semi-structured interviews with the researcher.

☐ **Option 2: Videoing care practices**

Allow the researcher to video you and the activities that happen around you. You may request for recording to cease at any time, and for recorded footage featuring yourself to be deleted. You do not have to do anything other than what you would normally do. You will then be invited to participate in an interview to review edited video footage to assist the researcher in understanding how you experience infection control practices.

☐ **Option 3: Making a video diary**

You are invited to keep a video diary of your infection control experiences, to give the researcher a deeper understanding of your healthcare experiences over time. You can discuss with the researcher how long you wish to continue this diary, including after your discharge from hospital. You will be invited to participate in ongoing interviews with the researcher to discuss the footage, and to help the researcher select clips that may, with your consent, be shown to health care professionals for quality improvement purposes. The researcher will loan you a simple video camera and give you a copy of the footage you create.

What happens to the data after it has been gathered?

The data is stored and handled at the University of Technology Sydney, in locked cabinets and on password-protected computers, housed in secure offices located in a CCTV protected special-security space.

As the study progresses, the researcher may need to keep in contact with you to collect more data, or contact you to ask you for permission to use these data for educational purposes within the study, or externally. The researcher may also contact you to share the results and findings of the study. If you are willing to be contacted for these purposes, please indicate so, and provide an email address and/or phone number below:

I **agree / do not agree** (please circle) to being contacted by the researcher about this study in the future.

Preferred contact email address:

Preferred contact phone number:

PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Patient or Visitor

Study Title: Strengthening frontline clinicians' infection control: A multi-method study to reduce MRSA infection and transmission
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Are there any risks?

There may be risks associated with this study that are presently unknown or unforeseeable. There may be some issues that, as a result of being observed, interviewed or filmed, may cause personal concern or discomfort. Participants experiencing such concerns have the opportunity to express their concerns to the researchers as well as to access counselling or support as required. Video-filming will be stopped in situations of crisis, and inappropriate data will be destroyed.

You can suspend or end your participation in the project at any time.

Are there any benefits?

This study aims to further knowledge and may improve future clinical practice in its aim to eradicate cross-infection of patients in hospitals. We cannot guarantee or promise that you will personally receive any benefits from this project, however previous participants in research of this kind have found it beneficial and have experienced a positive impact.

Confidentiality / Privacy

The people who treat you may know whether you have chosen to participate in this study. As is your private medical information, this study information will remain confidential and will be disclosed to others only with your permission, or except as required by law. Unless you state otherwise all information obtained in connection with this project and that can identify you will remain confidential. No information that will identify you will be made public. All records containing personal information will remain confidential and no information that could lead to your identification will be released. In any publication, information will be provided in such a way that you cannot be identified. Field notes, transcripts and visuals will be de-identified before publication. Only the researchers named above will have access to the data gathered and the results. It will only be disclosed with your permission and as required by law.

In some instances you may decide that you consent to the release of information where you can be identified. In this case the researcher will carefully discuss all aspects of this process and you can withdraw this consent at any time. The reasons for doing this are so that healthcare professionals or others watching the video footage can 'see' and experience care through your eyes and better understand how they can improve their care for all patients.

Original materials will be stored in a password protected computer and in locked filing cabinets. All of the researchers on this study fully understand the obligation to adhere to full confidentiality. All data and personal information will be stored, accessed and used in accordance with Commonwealth Privacy Laws and the NSW Health Records and Information Act 2002, as well as in accordance with University standards. Everything will be held securely at the University of Technology, Sydney, and at the Centre for Infectious Disease and Microbiology.

Compensation

If you suffer any injuries or complications as a result of this study, you should contact the study leader as soon as possible, who will assist you in arranging appropriate medical treatment. You may have a right to take legal action to obtain compensation for any injuries or complications resulting from the study. Compensation may be available if your injury or complication is sufficiently serious and is caused by unsafe drugs or equipment, or by the negligence of one of the parties involved in the study (for example, the

PARTICIPANT INFORMATION SHEET AND CONSENT FORM

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researcher, the hospital, or the treating doctor). If you receive compensation that includes an amount for medical expenses, you will be required to pay for your medical treatment from those compensation monies. You do not give up any legal rights to compensation by participating in this study.

If you are not eligible for compensation for your injury or complication under the law, but are eligible for Medicare, then you can receive any medical treatment required for your injury or complication free of charge as a public patient in any Australian public hospital.

Will taking part in this study cost me anything, and will I be paid?

Participation in this study will not cost you anything. You will not be paid for your participation in this study. Any equipment required for your participation in this study will be provided to you for the duration of the study.

What will happen at the conclusion of the study?

If the study is able to devise practices or approaches that lead to superior infection control, these will be publicised to other units and organizations, and to national and international policy bodies.

What happens with the results?

We plan to present and publish the results in peer-reviewed journals and at educational and professional conferences, nationally and internationally. In any publication or presentation, information will be provided in such a way that you cannot be identified, unless you give permission to do so. Results of the study will be provided to you, if you wish.

Complaints

This study has been approved by Western Sydney Local Health District Human Research Ethics Committee. If you have any concerns about the conduct of the study, or your rights as a study participant, you may contact: [INSERT DETAILS OF HOSPITAL PATIENT REPRESENTATIVE].

Contact details

When you have read this information, the researchers Su-yin Hor and/or Mary Wyer will discuss it with you and any queries you may have. If you would like to know more at any stage, please do not hesitate to contact Su-yin at Suyin.Hor@uts.edu.au, mobile: [REDACTED] or Mary at Mary.T.Wyer@student.uts.edu.au, mobile: [REDACTED]. If you have any problems while on the study, you can also contact Professor Rick Iedema, email: r.iedema@uts.edu.au, mobile: [REDACTED].

Thank you for taking the time to consider this study.

**If you wish to take part in it, please sign the attached consent form.
A copy of this information sheet will be given to you to keep.**

PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Patient or Visitor

Study Title: Strengthening frontline clinicians' infection control: A multi-method study to reduce MRSA infection and transmission

CONSENT TO PARTICIPATE IN RESEARCH

Chief Investigator: Professor Rick Iedema, University of Technology, Sydney

1. I understand that the researcher will conduct this study in a manner conforming to ethical and scientific principles set out by the National Health and Medical Research Council of Australia and the Good Clinical Research Practice Guidelines of the Therapeutic Goods Administration.
2. I acknowledge that I have read, or have had read to me the Participant Information Sheet relating to this study. I acknowledge that I understand the Participant Information Sheet. I acknowledge that the general purposes, methods, demands and possible risks and inconveniences which may occur to me during the study have been explained to me by _____ ("the researcher") and I, being over the age of 16 acknowledge that I understand the general purposes, methods, demands and possible risks and inconveniences which may occur during the study.
3. I acknowledge that I have been given time to consider the information and to seek other advice.
4. I acknowledge that refusal to take part in this study will not affect the usual treatment of my condition.
5. I acknowledge that I am volunteering to take part in this study and I may withdraw at any time.
6. I acknowledge that this research has been approved by the Western Sydney Local Health District Human Research Ethics Committee.
7. I acknowledge that I have received a copy of this form and the Participant Information Sheet, which I have signed.
8. I acknowledge that any regulatory authorities may have access to my medical records relevant to this study to monitor the research in which I am agreeing to participate. However, I understand my identity will not be disclosed to anyone else or in publications or presentations.

Name of participant _____ Date of Birth: _____

Signature of participant _____ Date: _____

Signature of researcher _____ Date: _____

Signature of witness _____ Date: _____

Appendix F: Media Release Form



Media Release Form

Centre for Health Communication
University of Technology Sydney
PO BOX 123
Broadway NSW 2007

Media format: ☐ Photographs ☐ Video ☐ Audio

Description: _____

Use and purpose:

- ☐ Academic publications ☐ Conference presentations and workshops
☐ Educational purposes ☐ CHC publications (internet and/or print)

Consent

Please note:

- You provide your consent by signing the release form where relevant
- You do not have to consent to all or any of the options on the consent form
- Withholding your consent in no way affects the medical care you receive from WSLHD

I consent to the Centre for Health Communication, University of Technology, Sydney, using and publishing the photographs, audio or video material detailed above, as specified.

It is understood that I have discussed with the researcher the particular photographs or video segments that I wish to release for the above purposes, as well as any features of the footage that I wish to remain identifiable or be de-identified through blurring.

It is also understood that any such materials (video, audio, and any other media) will be used with the highest integrity and discretion, with the intent to communicate responsibly and ethically, the subject matter contained therein.

Patient, Visitor or Staff:

Print Name: _____

Dept./Address: _____

Telephone: _____

Signature: _____ Date: _____

Parent/Guardian: A parent or guardian must sign this form if the participant is a minor or if the participant is hindered by mental or physical challenges.

Print Name: _____

Relationship: _____

Signature: _____ Date: _____

Withdrawal or Modification of Consent

I also understand that my consent can be withdrawn or modified at anytime by writing to: Su-yin Hor, Centre for Health Communication, University of Technology, Sydney. PO Box 123, Broadway, NSW 2007. Any changes to consent will be effective from the date of receipt by the Centre for Health Communication. Any existing resources (including external media) in which the material is used may not be withdrawn from circulation.

Appendix G: Statement of Co-authorship

The following people and institutions contributed to the publication of work undertaken as part of this thesis:

Mary Wyer, University of Tasmania, School of Health Sciences = **Candidate**

Rick Iedema, Monash University & University of Tasmania = **Author 1**

Su-Yin Hor, University of Tasmania = **Author 2**

Christine Jorm, The University of Sydney = **Author 3**

Claire Hooker, The University of Sydney = **Author 4**

Gwendolyn L Gilbert, The University of Sydney = **Author 5**

Matthew O’Sullivan, The University of Sydney = **Author 6**

Debra Jackson, Oxford-Brookes University = **Author 7**

Clarissa Hughes, University of Tasmania = **Author 8**

Katherine Carroll, Australian National University = **Author 9**

Gary Armstrong, Patient co-researcher = **Author 10**

Aileen Collier, University of Auckland = **Author 11**

Author details and their roles:

Paper 1, Researching Reflexively With Patients and Families: Two Studies Using Video-Reflexive Ethnography to Collaborate With Patients and Families in Patient Safety Research.

Located in Chapter 4: After a journal request for a substantial rewrite of the initial submission of the paper, the candidate prepared the first full draft of the new paper. The authors shared responsibility for the subsequent edits and the candidate prepared the document for publication. The candidate is the corresponding author.

Paper 2, Should I Stay or Should I Go: Patient understandings of and responses to source-isolation.

Located in Chapter 5: The candidate was the primary author and with authors 2,3,4,5,6,7,8,10 contributed to the idea, its formalisation and development

Paper 3, Involving patients in understanding hospital infection control using visual methods.

Located in Chapter 6: The candidate was the primary author and with author 1,2,3,4,5,6,7,9 contributed to the idea, its formalisation and development

Paper 4, Patient involvement can affect clinicians' perspectives and practices of infection prevention and control: A "post-qualitative" study using video-reflexive ethnography.

Located in chapter 7: The candidate was the primary author and with author 1,2,3,4,5 contributed to the idea, its formalisation and development

We the undersigned agree with the above stated “proportion of work undertaken” for each of the above published (or submitted) peer-reviewed manuscripts contributing to this thesis:

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